Recovering care

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Recovering Care
A contribution to a theory and practice of good care

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Foreword

This book is the result of a research project that started in 2005 as an idea to strengthen the theoretical foundation of psychosocial rehabilitation approaches in long-term mental health care. The rise of the recovery movement around the world has placed the experiences of people with psychiatric disabilities centre-stage. Over the past 20 years, a growing number of studies that collected the experiential knowledge of people in many countries have been published. I decided to use this experiential knowledge as the main source for strengthening and renewing the theoretical foundation of psychosocial rehabilitation, and for contributing to the development of recovery oriented care.

The data collected through studies in different countries and my own study in the Netherlands proved to be so rich that I decided to enlarge my scope beyond the field of psychosocial rehabilitation. From the narratives in the studies, much can be learned about what people consider to be 'good care'. In this study, care is not limited to specific kinds of treatment, therapy or counselling, but is taken as a general notion, referring to what a professional caregiver does in order to serve someone who needs help or support. I define good care as care that is perceived by the recipient as 'beneficial'.

On the basis of a conceptual analysis, a number of notions could be developed that contribute to a better understanding of what good care is. I believe these insights can be used not only to increase our understanding of good care, but also to improve the practice of good care. Since the subject of my investigation was people using mental health care services, the findings principally apply to this group. The results of this study can contribute to the development of services that support personal recovery and social participation. However, I am convinced that the results can also contribute to the improvement of care in general. In the discourse of 'good care', as unfolded in this book, not only personal and institutional dimensions come to the fore, but also social and societal dimensions. Good care should contribute to the recognition of people in vulnerable circumstances, strengthen their autonomy and improve their position as valuable members of the community.

Word of thanks

First of all I would like to thank the people who participated in this study (whom I do not mention by name because of privacy reasons). Their experiences form the heart of this book. I am very grateful for their willingness to share their stories with me. I was not only impressed by their frankness and openness, but also by the great courage and strength they showed in overcoming very difficult experiences.

Secondly, I would like to thank Professor Andries Baart, who has supervised this project over the past five years. I am grateful for his guidance, patience and wisdom.

I would like to thank the members of the PhD Committee of Tilburg University. Besides Professor Baart, the members were Professor Herman Meininger, Professor Tine van Regenmortel, Professor Frans Vosman and Professor Jaap van Weeghel.

I would like to thank my colleagues at the Research Centre for Social Innovation of Utrecht University for Applied Sciences and my colleagues participating in the research group "Care and contested coherence" of the School for Humanities at Tilburg University. I

thank them for sharing their knowledge, and for intriguing debates about the interests we have in common.

Finally I thank my children Jonathan, Daniel and Elisa for their patience and my wife Els for her love and everlasting support in bringing this study to a good end.

Jean Pierre Wilken - May 2010

The use of words

In this book I use the following expressions:
- When I use the word 'person' I usually refer to someone with a psychiatric disability. Sometimes I use words like 'client' but only to refer to a specific role, being a receiver of mental health or social services. I will sometimes also use words lake care receiver, service user or care recipient.
- When I use the word 'professional' I refer to a person in his role as provider of mental health services or social services. Sometimes I refer to the professional as a 'care worker' or 'care provider'. I will also use just the word 'worker'.
- In the stories professionals figure under different names, by function or discipline, like: psychiatrist, case manager, psychologist, psychotherapist, (social-psychiatric) nurse, counsellor, job specialist or vocational rehabilitation worker.
- When I speak about the things a professional does, I speak about actions, activities, support or services. Generally, I avoid the word 'intervention'. Although this is a common term in professional jargon, it literally means: coming in between; doing something from the outside. It is also associated with solving problems and crisis situations.
Sometimes I use this word in association with treatment or psychotherapy.
- The notion of 'need' I use to indicate the need for (professional) assistance or support.
A 'demand' is the appeal a person makes on (professional) assistance or support.
- Whenever a person in general is put in a masculine form, I also mean the feminine form, and vice versa, except in quotes from narratives. The citations from the narratives are anonymized.

Chapter 1 Introduction

1.1 A personal narrative

Already at an early age, people who were 'different' were part of my life. For a large part of my youth, I grew up in a home where my parents took care of people who, for some or other reason, were not able to take care of themselves. These people were 'excluded' from society, because they could not manage intellectually, they had psychological problems, or they had lost their house because of financial problems (often due to the fact that they lost a job or had a divorce). My father's house offered a safe place to stay, with no time limits and a high degree of acceptance. Regardless of background, disability and character, people where accepted as they were. I say 'my father's house', because my father was very much the leading caregiver in terms of personal relationships, whereas my mother took care of the household and finances. In 1960, my parents had founded their facility, a big wooden villa that could accommodate around 20 people. Prior to their establishing this facility, my father worked as a nurse in a psychiatric hospital. He left this profession as he could not live with the dehumanising way in which people were treated (Wilken, 1997). For more than 10 years, I experienced life in this amazing community. This considerably formed my personal narrative, and has contributed to my later professional and scientific work.

1.2 Care and presence

In later years, when I started to learn about the work of Joan Tronto, I recognised in the work of my parents the elements she describes as interrelated phases or parts of the care process: caring about, taking care of, care giving and care receiving. Tronto (1993) describes care as a value-guided practice. The values of my parents were certainly based on the Christian principle of compassion. They offered shelter and hospitality – a safe place where people were accepted as they were. They believed in the idea of *community* – people sharing with each other their daily lives and being meaningful to each other. Within that context, considerable personal attention was given to individual worries.

Tronto (1993) relates four elements to each of the phases of the care process. The first element is attentiveness. Care demands that there is attention to the neediness of the other. The second element is responsibility. One can only care if one makes oneself responsible for improving the situation of the person who needs care. The third element is competence. Without specific expertise in the domain in which the care should be given, one cannot offer care. The fourth element is responsiveness. The one receiving care should – literally – be receptive to that care. Tronto's conceptualisation of care is explicitly intersubjective. Caring is a process of answering to the demand of the other. This implies acknowledging that demand (attentiveness), feeling addressed (responsibility), knowing how to deal with the demand (competence), and giving a response knowing that it is not a one-way street, but a common endeavour (responsiveness). Care is based on a reciprocal involvement, the recognition that it is not possible without an effort of the other. The importance of this reciprocity was evident in our house – some people simply did not respond well to what was offered. These people usually stayed for a short while and then moved on, as they felt that their needs and demands were not satisfied to their liking. However, care can never come entirely from one end. Even if the other is completely helpless, communication is still there,

because the caregiver is addressed by (the helplessness of) the other. In this interaction, the fundamental reciprocity of the caring relationship is concealed.

At the beginning of this century, I became much inspired by the work of Andries Baart and his theory of *presence* (Baart, 2001). Again I recognised in the life of my parents many of the principles of the presence approach. Literally and symbolically, my parents were present in the (daily) lives of their residents. In this presence, the personal relationship was more emphasised than the professional angle. Their basic drive was their concern for suffering and wellbeing. In the theory of presence, care is considered as *concern*, which consists of four roots: *competent care* (doing what should be done), *carefulness* (doing not only what is needed, but doing it with attention and with regard for the needs of the other), *caring* (as a characteristic of the caregiver, which guarantees that what should be done is not only done with attention but is also continued – good care is faithful care), and *compassion* (an expression by which the caregiver presents him- or herself in a relationship) (Baart, 2008, p. 52).

In my opinion, presence is the broader concept in which Tronto's elements can be contained. Care emerges as a response to a need. With 'caring about' one starts worrying about someone, recognising his or her needs. 'Taking care of' means taking responsibility for improving the situation. 'Care giving' implies the actual delivery of a service in order to respond to the need. The care process, however, is not complete if the recipient of care does not acknowledge the receipt of the service.

Care as embedded in a relationship is an important concept in the presence theory of Baart (2001) and the theory of human loving care of Annelies van Heijst (2005), was a keystone of my father's work. His work was characterised by a high degree of personal attention. Attention to the person was never segregated from attention to the problem or need. My father took responsibility, sometimes by making firm statements, such as "We will certainly deal with this matter", and he always paired intentions with actions. He was always firm about "your word is your bond", and expected agreements to be met from both sides. As a nurse with years of experience in both general and mental health care, he was quite skilled, although he obviously did not have an answer to all the demands people expressed.

1.3 A community in the community

For my father, his facility was part of him and of his life. He created an environment, a small world, a haven, in which he and my mother found satisfaction for many years. My parents were much inspired by the ideas of the French priest Abbé Pierre, the founder of the world-wide Emmaus Movement[1]. One of Pierre's mottos was "You can only help yourself by helping others". He created small communities where people lived and worked together.

[1] The Emmaus Movement is an international non-violent movement which was created in 1949, when people from opposing social and economic positions decided to join forces in order to fight homelessness. Convinced that this "union of differences" would be an asset in the fight for a fairer world with greater respect for the dignity of human beings, these first companions founded an original and unique solidarity movement. The work of the Emmaus Movement is motivated by the simple sentences: 'serve first those who suffer most' and 'fight against the causes of poverty'. This founding principle of the movement is developed by local groups depending on the country and the context. Actually there are 306 member associations in 36 countries on 4 continents.

The more fortunate worked together with the less fortunate to help each other, but they also helped others in the greater community who were poor and suffering.

For my father, like for many other caregivers, his personal engagement and beliefs were crucial in his work. He strongly believed in Abbé Pierre's statement "One can only be happy by the joy which one is giving. Giving is receiving" (2006). He believed in doing 'the right thing': sharing sadness and joy with each other, helping people cope with their lives and helping them to positively apply their abilities. In my later work in the field of psychosocial rehabilitation, I was undoubtedly inspired by his ideas. My parents' house offered a *niche* for people who could not find, at a certain point in their life, a suitable position of their own. This niche I described later as an 'enabling niche', which serves two functions. One function is to offer safety and protection, as an oasis in the world's desert. The environment compensates for disabilities, so that they impede as little as possible in one's life. The second function is to help people discover, develop or use one's abilities (Wilken, Kaiser & Den Hollander, 1994).

Many residents used the facility as a resource for their recovery process and as a 'springboard' to find a partner, a job or a house. Then, at a certain moment in time, they did not need this special niche anymore. Others, mostly people with more serious disabilities, stayed for years and years. Their relationship with my father was often one that could be described as dependent. This was true for most of the staff as well. Although my father was a joyful man, it was also clear that he was in charge, and that his ideas formed the guiding principles for the facility This was the part I have always been most critical about. Dependency interferes with the basic principles of equality and reciprocity. Although it offers a basis to people, it also restricts them and prevents them from developing autonomy and using their own strengths. In later years I developed the notion of the right 'meeting space' or 'acting space', the psychological and physical space that is needed for individuals to develop and maintain individuality, freedom of communication and behaviour within a social system that is characterised by safety and interdependency (Wilken & Den Hollander, 1999).

Despite the small scale of 20 available places, the facility inevitably had some institutional features. Although as normal and homelike as possible, it still remained a professional facility, with a director, staff members, and house rules. What on the one hand was a safe haven, a special niche that responded to needs of different kinds, was on the other hand a place excluded from society. These are two sides of the same coin. Judged by the inside, one is included in and accepted by a mini-society; judged by the outside world, one is excluded from society. By staying inside, one belonged to a caring social system, but at the same time one was not fully part of the world.

Although I already mentioned that over the years many people found their way back to society, this was often more due to their own initiative than to a systematic care or rehabilitation policy. Considered in the context of the 1960s and 1970s, this was understandable. Ideas about social participation and rehabilitation and methodical ways to pursue goals to reach reintegration were not yet well known at the time. The care idea was very much guided by the traditional Christian values of charity and mercifulness.

Although one may say that the care my father offered was normative professional care, it was not very much characterised by reflectivity. In other words, it was *assumed* that by 'doing good' it was good care, but feedback was seldom obtained from the recipients from a meta-perspective. Responsiveness was certainly there in many cases, but it was a kind of responsiveness that was unconsciously experienced and not explicated or reflected upon. The type of responsiveness that was articulated quite well in my father's work (and which one finds again in the psychosocial rehabilitation model developed since the 1980s) was the idea of responding to the appeal that was made to use abilities and possibilities. Staying in this community meant that you had to return something to the community. It could be something small, like peeling the potatoes or doing the dishes. In this sense, there was reciprocity. At the same time, it emphasised to a great extent the individual's normal, healthy side. It also reflected the idea of 'life goes on' despite one's personal problems. Finally, it encouraged people to play social roles and to experience that activities are valuable and valued. This increased self-confidence contributed to the residents' positive self-image, which many of them had lost due to the events in their lives. Many of them moved on from this point, and succeeded in creating a life of their own.

Although the care was not *intended* to lead to these outcomes (which can now be considered good rehabilitation and recovery outcomes), for many users of this care approach it worked out this way. It supports my idea that Tronto's notion of care responsiveness can be refined by distinguishing different types of responsiveness. Responsiveness can be evoked and expressed in different ways. In chapter 5 I will describe on the basis of my empirical data a differentiated notion of care responsiveness.

1.4 Psychosocial rehabilitation

From my 18th year onwards, I combined studying social sciences with working in long-term mental health. After completing my studies, I worked as a practitioner, researcher, trainer and lecturer. My 'discovery' of the ideas of psychosocial rehabilitation, as developed by Geoff Shepherd and Douglas Bennett in the UK (Shepherd, 1984; Watts & Bennett, 1983; 1991), Bill Anthony, Michael Cohen and Marianne Farkas in the USA (Anthony, Cohen & Farkas, 1990) Detlef Petry (1989; 1993), Jos Dröes (1993), Jaap van Weeghel (1995) and others in the Netherlands, helped me to recognise and verbalise the work of my father and that of my own. It inspired me to find new ways for changing the traditional psychiatric practice and for helping people who have had a complicated life. The principles of psychosocial rehabilitation originated in the anti-psychiatry and democratic psychiatry movement in the 1960s and the de-institutionalisation movement in the 1970s. In the UK en the USA during the 1980s, the practices were connected to the development of community mental health services.

Together with my 'rehabilitation soul mate', Dirk den Hollander, and other colleagues, I started around 1987 to develop a comprehensive approach that on the one hand integrated best-practice elements as known from other countries, and on the other hand could be applied within the professional framework of the Dutch mental health disciplines (Wilken & Den Hollander, 1999; Wilken *et al*., 1994). Since that time, thousands of professionals have been inspired by this approach. The so-called CARe model[2] is widely used in the

[2] The Comprehensive Approach of Rehabilitation (CARe) consists of a set of principles, a methodology and a tool kit which provides professionals with a framework to build a collaborative relationship with and to provide

Netherlands, as well as in a number of other European countries. It has contributed to the improvement of the quality of life of many clients of mental health and social services.

Although it is applied with relative success, the psychosocial rehabilitation movement has unfortunately not changed mainstream psychiatry. Many mental health services do not use the body of knowledge of psychosocial rehabilitation. Some services do not use it at all, while others only use it partly. One of the main requirements of a comprehensive approach is that the principles be fully implemented both on the level of professional practice and on the level of the organisation of services. With low model fidelity on either of these levels, good results cannot be expected. Mainstream psychiatry is still dominated by the classical medical paradigm, with an emphasis rather on 'care giving' than on 'caring about' and 'care receiving'. The psychosocial rehabilitation movement has not been able to change the foundation of the system, but has made a difference in terms of humanising professional practice and making it more social-, recovery- and community-orientated.

My colleagues and I have often wondered why it is so difficult to make changes, even when all the 'stakeholders' seem to agree on the principles and the desirability of implementing the methods of psychosocial rehabilitation. Some people say that it takes (more) time to implement changes. The traditional model has been there for more than 150 years. As long as psychiatry is considered a medical discipline and a nature science, with a strong emphasis on the cure and a doctor–patient relationship, there will be little room for a major paradigm shift. A comparison can be made with the diagnosis of schizophrenia, which, even though it has been proven by several researchers to be scientifically invalid, still remains intact (see e.g. Blom, 2003; Boyle, 1990).[3] It is no wonder that the psychosocial rehabilitation model is the most popular outside the area of hospital and treatment services, for example in the domain of case management and supported living (Van de Beek, Dröes, Wilken, Zaat & Van Zuthem, 2006)

A weakness of the psychosocial rehabilitation model is that it does not have a strong scientific foundation. Rehabilitation is used for so many purposes and has so many connotations that it is difficult to say what it is and what it is not. Anthony, Cohen, Farkas and Gagne (2002) state the following:

> "As a result of the field's increasing popularity, the term psychiatric rehabilitation has become so overused that it is now necessary to define both what it is and what it is not' […]. Rehabilitation can be regarded as a field which has much been developed bottom-up, from the practice of daily routine. It emerged from different kind of 'needs': the urgency for human labour, the urgency for alternatives to institutional care, the need to change the professional behaviour towards people with psychiatric disabilities and so on. The solutions which were

services to persons in order to support personal recovery and social participation (Wilken & Den Hollander, 2005).

[3] Only recently there are some indications that in the next revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM) classification system, schizophrenia will be replaced by a new definition. A prominent scientist advocating this change is the Dutch psychiatrist Jim van Os. He proposes a new diagnostic system for psychosis, introducing the "salience dysregulation syndrome" (Van Os, 2009, p. 101).

found differ largely from place to place and were more 'practice based' than 'evidence based'." (2002, p. 3)

Although there is worldwide consensus on the guiding principles (Anthony *et al*., 2002), the rehabilitation umbrella contains a wide variety of approaches and methods. Only a limited number of these methods have been well researched. Research is mainly aimed at the effectiveness of methods, programmes or services, for example individual placement and support (IPS) in the domain of vocational rehabilitation (Bond, Drake, Becker & Mueser, 1998; Drake *et al*., 1999; Van Weeghel, 1995) and assertive community treatment (ACT) in the domain of outpatient care (Kroon, 1996; Marshall & Lockwood, 2000; Mulder & Kroon, 2009; Van Veldhuizen, Bähler, Polhuis & Van Os, 2008). Research is often aimed at more or less traditional outcomes, such as the duration of hospitalisation, the number of relapses and role functioning. But fortunately in more and more studies attention is also given to the evaluation of service users, in terms of their quality of life and service satisfaction. In general, users of rehabilitation services are more satisfied with home care services than with hospital services. Home care and comprehensive case-management services increase quality of life, for instance in the domain of social functioning.[4] Barton concludes in a review of rehabilitation studies that "longitudinal and outcomes research strongly supports the effectiveness and efficacy of psychosocial rehabilitation, but further research is needed to further refine intervention strategies" (1999, p. 530).

What is generally lacking is research that goes beyond the instrumental dimensions of a model (such as procedures and other organisational aspects) to investigate underlying human factors as well as contextual factors.[5] What struck me, for example, in a number of studies was that factors such as 'personal attention', 'frequent contact', 'at home' and 'small scale' are mentioned as being relevant, but that the precise meaning (both for service users and for professionals) was not investigated. My practical experience with the CARe model is that factors like these really make a difference. After all, a model or method is nothing more than a way of working that helps a professional to deliver good-quality care. However, the qualities of the professional as a person, the interaction with the client and the context in which they are working eventually lead to desired results. The curiosity of investigating this hypothesis initially inspired me to begin the research project that has ultimately led to this publication.

In the past century, psychosocial rehabilitation as a social movement has made considerable contributions to the normalisation and humanisation of psychiatry. Despite the fact that it has not altered mainstream psychiatry, psychosocial rehabilitation services have contributed considerably to the improvement of the quality of life of people with severe mental illness, supporting them to reintegrate into the community and to maintain a stable living. However, many rehabilitation services mainly remain based on a disability model, not paying enough attention to recovery possibilities, and on a professional model dominated by a vertical relationship between professional and client.

[4] See for instance the studies of Anderson *et al*. (1993); Van der Gaag (2003); Hogarty *et al*. (1997); Kroon, 1996; Muijen, Marks, Conolly and Audini (1992); Knapp *et al*. (1994); Thornicroft *et al.* (1998); Mullen, Burgess, Wallace, Palmer and Ruschena (2000) and Trieman, Leff and Glover (1999).
[5] Rare exceptions are ethnographic studies such as the one of Pols, Michon, Depla and Kroon (2001).

1.5 Recovery

Over the past decade, psychosocial rehabilitation has been considerably influenced by the recovery movement. A huge stream of experiential accounts and qualitative studies has provided many new insights into the dynamics of psychiatric disability. These insights are now being integrated into the field of psychosocial rehabilitation. The studies also show the importance of experiential knowledge in the process of rehabilitation and recovery, the importance of peer support, and the importance of equal relationships between service providers and service users. In different places in the world we see that these insights transform rehabilitation services into recovery support services (e.g. Barton, 1998; Curtis 2000; Substance Abuse and Mental Health Services Administration, 2006; Shepherd, Boardman & Slade, 2008).

The recovery movement has also influenced my own thinking as well as the design of this study. I am grateful for the inspiration from people like Judi Chamberlain (1997), Patricia Deegan (1988; 1996) and Wilma Boevink (2005; 2006; 2009).

For decades, scientific and professional practitioners have studied, written and spoken *about* people with mental illness. I think it is a fascinating emancipatory development that the voices of these people are now heard. People now change their role from passive object to active subject. They move from the role of a patient, client or consumer into the role of an expert-by-experience, a co-researcher or a peer specialist. A new type of (scientific or at least grounded) knowledge is sprouting: experiential knowledge that complements other scientific sources. For professional practice, it puts the relevance and importance of personal experiences and the conceptualisation of the person involved about his or her present and future situation in the centre of interest.

This is the reason why I decided to conduct an empirical qualitative study by collecting and analysing narratives of people who have experienced or are still experiencing serious mental health problems. Besides learning about factors hindering and facilitating recovery, I wanted to learn from their experiences of professional services. I was convinced that by thoroughly analysing data from a 'client's perspective', evidence could be found about factors that really contribute to health and wellbeing.

A special focus of my study was to discover which contributions of professional care providers proved to be helpful in the process of recovery. For the research design, I decided to collect evidence on the basis of the experiences of service users only, and not from professionals, in order not to 'contaminate' the experiential data. This part of the research project was preceded by a review of qualitative recovery studies that have been published over the past 20 years, in order to learn as much as possible about dimensions of recovery, as revealed by these studies. On the basis of the literature review and the analysis of the data from the perspective of service users, my next – and exciting – effort would be to translate the key elements of good professional care into a discourse that professionals can use to support recovery. If this effort is successful, this could also contribute to the strengthening of the theoretical foundation of psychosocial rehabilitation or recovery-focused care, as well as to a renewal of the rehabilitation practice.

1.6 Obstacles to good care

The aim of this study was to contribute to changing the current practice in mental health care and social work, there where it is impeding the provision of 'good care'. I define 'good care' as "Care that is perceived by a receiver of care as beneficial". Nowadays, there seems to be a number of obstacles in the way of providing good care. In this section I briefly discuss the obstacles caused by the dominant discourse of professional care. This discourse in part has its own dynamics, but is also influenced by a larger socio-political context.

In the dominant discourse of professional care, both in health care and social work, the focus of professional education and practice is on (a) the scientific and methodical knowledge of the professional, considered to be the only source of knowledge; and (b) problems and deficits. Placing emphasis on the knowledge of the professional carries the risk of ignoring other sources of knowledge, such as the experiential knowledge of service users themselves.

The focus on the knowledge of the professional is based mainly on positivistic science. Especially in psychiatry, which has been positioned as a medical discipline over the past century, social aspects have been largely ignored. The emphasis was on 'clinical data', statistics and evidence promoting the rationalisation of services. To a large extent, human relationships and social contexts had moved out of sight. This included the relationship between the professional and the care recipient, but also aspects of the institutionalisation of care.

Focusing (only) on problems and deficits carries risks. The first risk is the separation of the problem from the person, whereby the person as a whole and the context of his or her life are ignored. The person is fragmented, which may contribute to further alienation and may damage his or her identity and autonomy. A parallel process occurs, as care is also organised in a fragmented way, divided between different professionals and services that are all 'specialised' in a particular part. The second risk is that professional care is reduced to 'fixing a problem', which narrows care down to an instrumental act, and additionally creates the illusion that all problems can be 'fixed'. 'Taking care of' here obtains the meaning of 'fixing a problem'. Care is here disposed of a socio-ethical framework. This approach also brings with it the connotation that the problem is the object of care and that the professional is the one who has the solutions. This puts the person receiving care in a passive role. This focus excludes the own strengths of this person and his or her environment in order to overcome problems with the least professional intervention. It is also a focus on control (from the side of the professional) instead of on development (on the side of the person concerned).

I became more conscious of the 'deficit perspective' through the work of Charles Rapp from Kansas University in the USA (Rapp & Gosha, 2006). According to Rapp & Gosha, "social work and other helping professionals created a profound tilt towards the pathological. Because of the subtle ways in which this bias is expressed, its contours and consequences must be examined to set the stage for a different perspective" (Rapp & Goscha, 2006, p. 4).

The socio-political context, in which the discourse of care is embedded, is dominated by instrumental rationality: the effective and efficient arrangement of means according to specified objectives. All professional activity is judged according to standards of maximum efficiency. The risk is that these standards are disconnected from any moral considerations.

The emphasis is on the 'how' and the importance of the ultimate result of acts (the why or where to) disappears (Meininger, 2002; Taylor, 1992).

In the rationalities of modern professional care, these societal norms have been penetrated. Professionals are supposed to strive for effective and efficient (fast) achievements, find quick solutions and provide 'damage control'. Users of services have to adapt to these norms, or else they are excluded from the services. This phenomenon has occurred over the past decades. People have dropped out of the social and health service system, and sometimes even out of the housing system, becoming homeless. Although attempts are made to 'repair' this by creating more assertive outreach services, much damage has been done. People have been disappointed and have turned their back to professional caregivers. In reference to Tronto, one can certainly call this negative responsiveness. Here, there is no care at all.

As another result of rationality, in the last decade in the Netherlands, as in other European countries, the neoliberal funding system, based on financial accountability rather than on client outcomes, has placed the emphasis in the health system on financial management. Care facilities are considered part of a market economy. Keywords nowadays are efficiency and competition. Professionals are obliged not only to account for all the time spent during their working hours, but also to allocate this time to categories of actions labelled as 'products'. These actions are related to a particular diagnosis, a standardised assessment of needs, and a standardised programme connected to this assessment. A contradictory effect of this focus is that that all contact between professional and client is per definition 'time limited', but that at the same time documentation of contact time on an electronic system requires considerable time. This means that overhead time increases, sometimes by as much as 30%. The system looks efficient, but in fact it is not. It again leads to stigmatisation by diagnosis, a focus on the disorder or the disability rather than on the strengths. Alleged objectivity threatens an intersubjective care approach. It also keeps the professional from working with a client in a constructive relationship and in a flexible time perspective (Petry, 2007; Plemper, Van Vliet & Van der Laan, 2003; Tonkens, 2003).

1.7 Counteracting movements

Over the past decades, a few movements that provide a countervailing power have emerged both in practice and in science.

A number of sociologists and philosophers have published studies indicating a *general need in postmodern society for ethics and morality*, against the background of fundamental questions about personal identity and the meaning of life (e.g. Meininger, 2002; Ricoeur, 1990; Taylor, 1989; Van den Besselaar, 2009; Van den Brink, 2004). More specifically, a number of authors have published studies in the domain of health care and social work that criticise and reconsider the work of professionals and the way in which professional institutions are functioning (e.g. Baart, 2001; Tonkens, 2003; Van der Lans, 2008). A number of scholars have developed ideas about normative professionalism, which provide a new ethical base for professional work (e.g. Baart, 2001; Jacobs, Meij, Tenwolde & Zomer, 2008; Kunneman, 1996; Tronto, 1993; Van den Besselaar, 2009; Van Heijst, 2005; Van Houten, 2008; Vorstenbosch, 2005).

An important countervailing power comes from the *consumer movement*. Thanks to the efforts of consumer organisations, there is now political consensus on the importance of consumer participation in health care. In many countries, this has been legislated. Consumers can influence the policy of service providers, and theoretically also change it. I say theoretically, because in many cases consumers do not yet have enough power to really be influential.

In mental health care, a countermovement is formed by the recovery movement, which is constituted by consumers and ex-consumers demonstrating that recovery from serious mental illness is possible – ironically, as Patricia Deegan (2002) puts it, even 'despite' the mental health system. As demonstrated in Chapter 2 of this book, numerous studies on recovery show that the majority of people suffering from a mental disorder manage at a certain moment in time to live a stable and satisfying life, with or without psychiatric symptoms. As research data are increasing, much more is learned about the different factors that contribute to a recovery process. More information on the area in which professional care obstructs recovery and where it is supportive is also gained.

The aim of this study is to contribute to this growing body of knowledge on recovery and the way in which professional carers can make a valuable contribution. Although the empirical data were collected within the domain of mental health, specifically by using the experiential knowledge of people with severe mental illness, the ultimate aim was to find grounding concepts for a general theory of 'good care', which could contribute to the improvement of professional health care and social services, regardless of specific needs related to a particular illness or disability.

This study does not stand in isolation, but builds on other studies published in the past decennium, especially the *Theory of presence* (Baart, 2001) and *Human loving care* (Van Heijst, 2005). A grounded theory of good care, to which this book contributes, will hopefully contribute to a countervailing power, putting good care and desired client outcomes at the beginning *and* at the end of the system.

The title of this book, *Recovering care*, reflects the double desire that professional care will recover from its present deformations, get rid of the obstacles that stand in the way of good care, and truly support the recovering processes of people with a serious illness or disability.

1.8 Research objectives and methodology

In summary of what has been said above, the motives for this study were the following:

1. Although the rehabilitation movement has made many positive contributions in terms of humanising professional practice and making it more social, recovery- and community-orientated, there is still a lack of theoretical foundation for the psychosocial/psychiatric rehabilitation model and a lack of scientific evidence for professional practices based on this model.
2. In a time when care is dominated by positivistic science, efficiency and bureaucracy, there is a need to define good care and to identify essential elements of good care and its ethical basis.

The research questions in this study were formulated as follows:
1. What can one learn from longitudinal studies on the course of serious mental illnesses and from qualitative studies on recovery processes and factors contributing to recovery?
2. Which knowledge can be added to the basis of a qualitative study on recovery stories in the Netherlands?
3. What are apparently the most important elements of recovery-focused care in mental health?
4. Which theoretically understood learning can be drawn from the data on essential elements of good care?

The purposes of this study were the following:
1. To contribute to knowledge about recovery and professional support for recovery of persons with serious mental illness.
2. To contribute to a theory of good care (for vulnerable people) on the basis of an ethic of care.
3. To contribute to practices of good care by eliciting essential elements of good care.

This book contains the results of three research projects. The first is a systematic review of international longitudinal and qualitative studies on serious mental illness and recovery (Chapter 2). The second is a narrative study on the experiences of people with a psychiatric history in the Netherlands (Chapters 3 and 4). The third is a (secondary) analysis of the data of the Dutch experiential study by connecting these findings to existing theoretical concepts and searching for constituting elements of a theory and practice of good care (Chapters 5 and 6). An outline of these chapters is given in paragraph 1.9.

This study as a whole and in particular chapters 3 and 4 is qualitative by nature. The details of methodology and procedures used for each part of the study are explained at the beginning of each chapter. Empirical data are used for conceptual analysis, using the methodology of grounded theory. Grounded theory is a qualitative research approach that enables the eliciting of new insights into phenomena and novel theoretical formulations from data (Glaser & Strauss, 1967). Grounded theory procedures are described in Strauss (1987), Strauss and Corbin (1990) and Charmaz (2000).

In most of the experiential studies reviewed in Chapter 2, grounded theory was used to collect and analyse the data. In my qualitative (meta-)analysis I merged the data provided by all the studies, using basically the same methodology of constant comparison. In the empirical study described in chapters 3 and 4, the transcribed interviews with participants were analysed using a close-reading protocol developed on the basis of the discourse analysis methodology as described by Fairclough (1995; 2003). Using a grounded theory approach, a constant cross-comparative analysis was done to identify themes and to develop the categories that are presented in Chapter 4. While chapters 2 and 3 are basically deductive by nature, chapters 4 and 5 are more inductive. In Chapter 5, the inductively acquired information is merged in a deductive way with information from relevant theoretical models.

For the theory building in Chapters 5 and 6, I used a theoretically inspired but heuristic framework consisting of a professional discourse, the aims of this discourse and the position

of the professional in the light of the discourse. I discern logic, relevance and practice. The elements emerging from the conceptual analysis of the data of the Dutch narrative study were clustered into meaningful concepts, which constitute the *logic* of the discourse of good care. With regard to relevance, I investigated the qualities that came to the fore on the basis of this logic. With regard to the practice of good care, I investigated the acts, methods and approaches that form a good instrumental translation of this logic. The results in Chapters 5 and 6 fit with a substantial theory that covers a larger domain than the empirical research in chapters 3 and 4. The results and conclusions have a broader and more general significance. When the results of the third study are considered in terms of that of the first two studies, it frames these findings in a broader perspective without affecting its logic. Yin (2008) speaks about *analytic* or *theoretical generalisation* (cited in Smaling, 2009, p. 8). The theory, as developed in the last chapter, may serve as a vehicle for generalisation to new practices fitting within this discourse. At the same time, in accordance with the principles of grounded theory, future data will complement and probably change insights. The theory will therefore continuously change and develop.

By connecting the findings of the data analysis of the experiential study to other scientific sources and theoretical concepts, I strived for a sufficient degree of *communicative generalisability* (Smaling, 2003; 2009), leaving it to the reader to decide whether he or she considers the results relevant. A meta-theoretical framework consisting of multiple layers was constructed; serving theory and practice for long-term care in general and for recovery-orientated mental health care in particular. This framework has, besides knowledge and theoretical relevance, also practical and social relevance.

In qualitative research, verification refers to the mechanisms used during the process of research to incrementally contribute to ensuring reliability and validity and, thus, the rigor of a study. These mechanisms are woven into every step of the inquiry to construct a solid product by identifying and correcting errors before they are built into the developing theoretical model and before they subvert the analysis. Morse, Barret, Mayan, Olson and Spiers (2002) state that if the principles of qualitative inquiry are followed, the analysis itself is self-correcting. In other words, qualitative research is iterative rather than linear, so that a good qualitative researcher moves back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data-collection strategies and analysis. Data are systematically checked, focus is maintained, and the fit of data and the conceptual work of analysis and interpretation are monitored and confirmed constantly. Verification strategies help the researcher to identify when to continue, to stop or to modify the research process in order to achieve reliability and validity and ensure rigor. Morse *et al*. state: “Research is only as good as the investigator. It is the researcher’s creativity, sensitivity, flexibility and skill in using the verification strategies that determines the reliability and validity of the evolving study” (2002, p. 10). In this study I have tried to be a good investigator, using within the conduct of inquiry different verification strategies to ensure both the reliability and the validity of data.

Internal validity was promoted by following the grounded theory approach of Glaser and Strauss (1967), by using standardised methods (such as field notes) and computerised programmes to categorise and analyse the data, and by discussing data with participants and

fellow researchers.[6] External validity was pursued by giving precise descriptions of the position of the researcher, the participants, the context of this study and the methods and techniques used. I strived at ensuring methodological coherence; sampling sufficiency; the development of a dynamic relationship between sampling and data collection and analysis; theoretical thinking; and theory development. In Chapters 5 and 6 I also used the method of theoretical triangulation, in which several relevant theories were used to develop a consistent theoretical framework.

Glaser (1978, p. 3) states that valid theories are "well developed and informed, they are comprehensive, logical, parsimonious, and consistent". In Chapter 5, with its emphasis on theory development, I moved with deliberation between a micro-perspective of the data, as used in chapters 3 and 4, and a macro-perspective of conceptual and theoretical understanding. In this way, theory was developed through two mechanisms: (1) as an outcome of the research process (i.e. grounded), rather than being adopted as a framework to expedite the analysis along; and (2) as a template for comparison and further development of the theory.

In order to achieve validity, the results of the analysis and the conceptualisation of a theory of good care were repeatedly and critically examined by and thoroughly discussed with Professor Andries Baart, who I gratefully thank for this.

1.9 Composition

The book consists of six chapters. After this introductory chapter, the results of a systematic review of recovery studies over the past 15 years are presented in Chapter 2. The chapter starts with a summary of the data of 15 longitudinal studies between 1969 and 2001. Thereafter, a review of 28 qualitative studies published between 1993 and 2009 is presented. The chapter concludes with the results of a cluster analysis.

In chapters 3 and 4 the results of a qualitative empirical study, based on the analysis of 13 narratives, are described. This study was conducted among people with (long-term) mental health care experiences in the Netherlands, focusing on both their personal story and their conceptions about what effectively helped them in their recovery process. The aim of this part of the study was to find out what happened to them in terms of life events and mental disorder, how the person dealt with vulnerability, and what the role of the environment was. I was especially curious to find out which factors hindered or facilitated progress. Within this analysis there was a special focus on the role of mental health care. Which services did the participants perceive to be helpful? What is considered by the participants to be 'good care'? Chapter 3 describes aspects of vulnerability and recovery that came to the fore from the analysis. In Chapter 4, the results of a secondary analysis are presented. In this analysis I searched for essential notions in the interaction between the narrators and professional caregivers. I investigated themes in the stories that were associated with good care. These themes could be clustered into five categories.

[6] Members of the research group of the Research Centre for Social Innovation at Utrecht University of Applied Sciences and the research group Care and Contested Coherence of Tilburg University , Netherlands, of which the author is a member.

In Chapters 5 and 6, the insights of this study are developed into a theory of good care by connecting them to other relevant studies and theories. The categories of professional support expounded in Chapter 4 are placed in a discourse of good care. This discourse has an ethical base that is grounded in the theory of recognition (Honneth, 1995) and care ethics (Baart 2001; Tronto, 1993; Van Heijst, 2005). Central to the discourse is the assertion that good care is embedded in a personal-professional relationship. Within this discourse a practice is established, with at its core the co-creation of an interpersonal space on the basis of the notion of care responsiveness.

Chapter 2 Recovery: results of an international review

In this chapter I explore the concept of recovery. I review the literature and discuss the current body of knowledge on recovery. I answer the following questions: What is recovery? What is known about the course and outcomes of a recovery process? What factors hinder and facilitate the process? The answers to the last question in particular lead to the role professional care can play in facilitating the recovery process. I also attempt to come to grips with the dynamic character of the concept of recovery by constructing a multidimensional model.

2.1 Introduction

Over the past century researchers have been wondering about the course of serious mental illnesses, especially schizophrenia. These studies mostly had a clinical angle. Recovery was perceived in a medical sense, although also social dimensions were taken into account. Many longitudinal studies have been conducted, especially until the eighties (e.g. Ciompi, 1980; Strauss & Carpenter, 1974; Strauss *et al.*, 1978)

From the late eighties of the last century onwards a growing number of personal accounts were published. People started writing about their own recovery process (e.g. Anonymous, 1986; Boevink *et al*., 2002; Boevink, 2005; 2006; Deegan, 1988; Granger, 1994; Leete, 1989; Lovejoy, 1984; Walker, 1986)

From the nineties onwards scientists and professionals became increasingly interested in the phenomena of personal recovery, and conceptual writings started to appear (e.g. Anthony, 1993; Fisher, 1994; Fisher & Ahern, 1999; Hatfield & Lefley, 1993; Hogan, 1994; McGorry, 1992; Ragins, 1994).

Around the turn of the century a growing number of qualitative experiential studies were published (e.g. Borg & Davidson, 2008; Brown & Kandirikirira, 2007; Spaniol, Wewiorski & Gagne, 2002; Topor, 2001; Young & Ensing, 1999). These qualitative studies are conducted against the background of the insights of the conceptual writings and mostly include an analysis of personal narratives.

In this review I group two types of studies: the 'traditional' longitudinal studies, which are mostly focused on objective measures such as symptomatology and functioning, and the modern qualitative experiential studies, which are mainly focused on subjective experiences.

Paragraph 2.2 gives a description of the methodology and the procedures that I used for this study. In paragraph 2.3 the notion of recovery is introduced on the basis of personal account literature (2) and conceptual writings (3).

Paragraph 2.4 entails a review of the longitudinal studies. The knowledge stemming from qualitative studies is discussed in paragraphs 2.5 to 2.8. The studies shed more light on the course of recovery processes and the factors that are important in these processes. In

paragraph 2.9 I discuss relationships between different factors of recovery. The chapter concludes with some conclusions and reflections (paragraph 2.10).

2.2 Methodology and procedure

This chapter is based on two systematic literature searches (Petticrew & Roberts, 2006). The first was conducted in 2005 and the second in 2009. The searches were conducted by searching the databases of Academic Search Premier, CINAHL, Cochrane Library, PsycINFO, PubMed and Google Scholar, using different combinations of the terms 'recovery', 'mental illness', 'psychosis' and 'schizophrenia'. The searches were aimed at both longitudinal studies and qualitative narrative studies. Fifteen longitudinal studies were found, including more than 3 700 subjects.

Over the past decade an increasing amount of personal accounts has been published in journals, books, newsletters and on the internet. These stories illustrate the many and varied ways in which recovery takes place. In my literature search I chose not to include publications by individuals, but to select studies that (a) concern a systematic review of autobiographic literature or (b) concern cohorts of people, using structured or semi-structured interviewing, either individually or in focus groups. Furthermore, studies had to meet the following criteria:

1. The study should have a solid scientific research design.
2. The goal of the study should be the identification of important recovery factors drawn from the personal experience of people in the process of recovery or who have recovered from a serious mental illness.
3. The scope of the study should be rather wide, starting with the personal story of the person, and not limit the study to a predetermined area of recovery. For example, studies that focused only on the area of employment were excluded.
4. Subjects had to have a history of severe mental illness. Criteria included having to cope with an illness for more than two years, and having a diagnosis such as a psychotic, depressive or bipolar disorder.

On the basis of these criteria, in total, 28 narrative studies were selected, comprising more than 950 subjects. The literature on the qualitative studies was analysed by looking for descriptors of processes, factors and outcomes. The factors were organised into meaningful clusters, using a grounded theory approach (Charmaz, 2000; Glaser & Strauss, 1967). This resulted in a multidimensional model.

The findings of the first search were published in the book *Rehabilitation and recovery* (Wilken & Den Hollander, 2005) and in articles in the *Dutch Journal for Mental Health Care* (Wilken, 2006a) and the *Journal of the Norwegian Psychological Association* (Wilken, 2007a). The second search was mainly focused on narrative studies that were published since 2002. The data of this search were added to the data of the first search. Cross-comparative analysis showed that the clusters of the multidimensional model were valid, but one separate cluster was added (reconstructing identity). Also, some refinements could be made.

Methodological notes

(1) A number of longitudinal studies on schizophrenia, with a follow-up of five, ten or more years, suggest that more than half of the people had a full or partial recovery (Bleuler, 1978; Harding, Brooks, Ashikaga, Strauss & Breier, 1987a; Harding, Brooks, Ashikaga, Strauss & Breier 1987b; Vailliant, 1978; World Health Organization, 1979). However, there are a few problems with these studies. Firstly, there is the problem of the diagnosis itself. Criteria tend to change over time. The same patient can also be diagnosed differently by different clinicians. Even the same clinician may change his or her diagnosis for the same patient over time (Van Os, Galdos, Lewis, Bourgeois & Mann, 1993; Van Os & Neeleman, 1998. In an interesting study, Boyle (1990) evaluated the validity of schizophrenia as a scientific construct. She concluded that there is, apparently, no empirical base. However, she states "paradoxically, a strong theoretical network exists, which keeps the construct very much alive" (Boyle, 1990, p. 117). Others, such as Tucker (1998), Vlamink (2002) and Blom (2003), also 'dismantle' the validity of schizophrenia, as well as other diagnostic categories. Van Os considers the concept of schizophrenia to be wrong and harmful. He pleads for a new system of clusters of symptoms, which also has more relevance for treatment and recovery (Van Os, 2003). Secondly, there are different understandings of 'recovery'. There is no agreement on its scientific definition. Thirdly, the longitudinal research studies study a certain period in a person's life (Harding *et al*, 1987a). Usually, an assessment is made at baseline at T-0, and at follow-up at T-1 and/or T-2. The period in-between is considered to be the 'course' of the illness, or the 'course of recovery'. The data on T-1 or T-2 are considered to produce the 'outcome' of the recovery process. However, in reality, a recovery process may have begun long before T-0. It may also just be starting at or after T-2. The data are therefore not very reliable. Fourthly, the outcome measures were quite limited to symptoms and social functioning.

(2) A problem with the literature on recovery is that there are inconsistencies in the way key concepts are described (Ochocka *et al.* 2005). Often, researchers and writers use different words to refer to similar concepts. For example, Jacobson (2001) describes connections or interconnectedness as an internal factor for recovery, which, according to Ralph (2000), is an external factor. Furthermore, several recovery studies and conceptual pieces do not link key concepts, showing the interrelationships between the concepts. The studies that attempt to clarify relations come up with different models, which make it difficult to link key concepts. A factor that has influenced data collection is that the narratives that were collected were mostly of people with positive recovery experiences. People who are not capable of verbal communication and people who are very disabled and/or ill and are presumably *not* recovering are mostly absent in the studies. This might cause a too positive bias as far as the probabilities of recovery are concerned.

Yet, a strong aspect of these narrative studies is that most of them used the same grounded theory approach, which makes it possible to cumulate data and to gain increasing insight into the phenomenon of recovery. These data provide a general outline of how processes envelop and show mounting evidence of essential 'common factors' in these processes. And although we do not yet know exactly how the interactions of these factors work on an individual level, it is yet a great step forward that we know where to look, and thereby can support individuals better in their recovery process.

2.3 The notion of recovery

What is recovery?

Anthony (1993) traces the origin of the recovery construct in the USA back to the 1970s. During that period, a new self-help ideology was becoming increasingly popular. A number of factors influenced this self-help movement, such as the human-rights movement; the psychosocial rehabilitation movement and the wish to reduce stigma. Anthony challenged the rehabilitation movement and the mental health system to really address people's multiple residential, social, vocational and educational needs and wants. He defined recovery as follows:

> A deeply personal, unique process of changing one's attitudes, values, feelings, and goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life. (Anthony, 1993, p. 15)

Patricia Deegan (1993) wrote a moving account of her own recovery process:

> It is very important for me to say that, yes, I have a disability, but that does not make me a disabled person. I have learned that it is possible to lead a worthy and healthy life despite my disability. People often think that the two don't go together, but they're wrong. I have a psychiatric disability and lead a full and healthy life. I succeed in this because I am working on my recovery. I believe that I will recover [...] One of the lessons that I had to learn was that recovery isn't the same as being cured. After having lived with my illness for 21 years, it hasn't gone away. I don't suppose that I will ever be cured, but I am recovering. Recovery is a process, not an end or goal. Recovery is an attitude, a way of getting through the day and tackling the challenges that come my way. [...] Knowing what I can't do lets me see the numerous possibilities still open to me.

Deegan (1988) also writes that recovery is something that people with disabilities have to do themselves, while rehabilitation is something that care workers can do to support the recovery process. This is confirmed by Perkins (2002, p. 25) who states: "Recovery is not something done by mental health practitioners; it is the personal journey of individuals. Professionals may facilitate it but they cannot do recovery 'for' or 'to' people".

Other people define recovery as follows:

> "Recovery is an ongoing process of growth, discovery, and change." (Stocks, 1995, p. 90)
>
> "A recovery paradigm is each person's unique experience of their road to recovery.... My recovery paradigm included my reconnection which included the following four key ingredients: connection, safety, hope, and acknowledgment of my spiritual self." (Long, 1994, p. 4)
>
> "'What there is now that is new is the beginning of trust that the bad times will pass and the underlying strength will prevail. What there is now is insight about how externals affect me and how to better manage myself in connection with outside

factors. What there is now is acceptance. I reinforce what I learn with an annual life review." (Caras, 1999, p. 2)

Recovery seems to be a very individualised process. Therefore it seems impossible to do research beyond the N = 1 design. However, it is important to develop some common framework that enables persons with psychiatric disabilities, researchers and professionals to understand the recovery process better and to help integrating notions of recovery in the fields of mental health care and psychosocial rehabilitation.

Longitudinal studies in which people with long-term psychiatric problems were followed for more than 20 years (e.g. Harding *et al*., 1987a; 1987b) show that more than half the people had a full or partial recovery. Some people displayed fairly severe symptoms of basal dysfunction, while others had almost no symptoms at all. Many people led socially integrated lives. How the process works is something that we do not as yet fully understand. However, as can be concluded from this review, a number of essential ingredients can now be identified.

The word 'recovery'

Some people use the term 'recovery process', yet others refer to 'a process of learning' or 'a process of growth'. Some say that they do not feel as if they are recovering, but that they are coping with their mental health problem. Others refuse to speak about recovery

"I don't believe I had an illness but recovery implies I did have one."

"'I don't see my madness as undesirable, so what is it that I need to recover from?" (citations in O'Hagan, 2003, p. 16).

The verb 'to recover' has many meanings; it can mean to regain, to rescue, to reclaim, to liberate. The verb 'to recover' has a number of meanings. Recovery can be related to getting back possessions (e.g. one's kingdom), economics (a recovering economy, a rallying stock exchange), health (to recover from an illness) or voice (being able to speak again). The connotations of 'recovering' are that of regaining, getting back, reinstating and getting well (Topor, 1001, p. 55). In Dutch, recovery is used to refer to a personal healing process, as well as to a social process, for instance to the re-establishment of disturbed or broken relationships. Social roles can also be recovered. Also, recovery can be synonymous with reparation, mending or restoration.

It is interesting to notice that 'rehabilitation' is one of the synonyms of recovery. The difference is that recovery is more of an active process on the part of the person concerned, while rehabilitation is an active process on the part of others who are rehabilitating someone or something. The Swedish word for recovery is 'återhämting', while the reflective verb is 'återhämta sig', implying the active role of the person him- or herself in the recovery process. The French word 'récupérer' means, among other things, finding one's strengths again, while 'récouvrer' refers to returning to a previous state (of health). Rehabilitation (in different languages) also means reconstruction, rebuilding, redevelopment, returning to its original state or to a new, better state (compare 'recreation'). Rehabilitation in its ideological meaning means 'to recover from grievance'. In a semantic sense, recovery and rehabilitation can be complementary.

Recovery can imply a return to a former identity or the emergence of a new one. Both positions can be found in the literature on recovery in mental health. Recovery is mainly used as a process notion. Someone is on his or her way to living a satisfying, hopeful and contributing life. This way is described as a path or a journey. Other authors also use recovery as an end state: the road *to* recovery. In this sense, recovery is the goal to be achieved.

Definitions of recovery

It is remarkable that in classic literature on psychiatry, the recovery concept is seldom defined. In the professional view, for long dominated by a medical view, a person could either be cured from a psychiatric illness, was diagnosed to have a chronic illness or became chronic over the years. Cure was mostly defined as the absence of symptoms, measured by clinical methods and no remaining (need for) treatment. In addition, the social effects or disabilities resulting from the illness were taken into consideration. From a psychodynamic point of view, whether or not the person shows 'insight' is still another factor in determining recovery.

An absolute definition of recovery in a medical sense would be that recovery is defined by the absence of symptoms, treatment and resulting social effects. Some researchers have devised a system for grading the extent of recovery. A person may be cured although his or her social situation has not altered. Similarly, a person can be trained to improve skills and function better, although the symptoms remain (McGorry, 1992).

In classification systems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association (1994), a number of diagnoses contain criteria implicating chronicity, such as 'schizophrenia'. Over the years, the different editions of the manual reveal less and less certainty about the criteria of duration. On the one hand, duration of symptoms is used to come to a certain diagnosis, e.g. a presence of symptoms for at least six months as one of the criteria for schizophrenia. On the other hand, the diagnosis itself suggests a long duration of the illness. As for the probability that patients may recover, the writers of DSM-IV say that it depends on how the disorder is defined but they also state that "complete remission (i.e. a return to full premorbid functioning) is probably not common in this disorder" (APA, 1994, p. 282),. This line of thinking is partly based on Kraepelin's natural history model (Kraepelin, 1971). He defined psychiatric diagnosis by the nature of its course and outcome. His 'dementia praecox', later named 'schizophrenia', was however a cluster of different syndromes considered as representing a single disease. A number of different outcomes were narrowed down to a small range of outcomes. Research data of later studies proved that people diagnosed with 'schizophrenia' do indeed have different outcomes (Ciompi, 1980; Strauss & Carpenter, 1974).

There is no agreement on the scientific definition of recovery. Already almost 40 years ago Kraepelin made a distinction between "cure" and "recovery with defect" (1971, p. 186). "Cure" means the total absence of all signs of a mental disorder. "Recovery with defect" means that even if the most disturbing symptoms have disappeared, there are still signs that are associated with the disease. This recurs in later literature both as "best outcome" and "second best outcome" (World Health Organization, 1979, p. 67), as "'total recovery" and

"social recovery" (Warner, 1985, p. 43), or as "'symptomatic recovery" and "social recovery" (Liberman, Kopelowicz, Ventura & Gutkind, 2002, p.257).

Liberman *et al*. (2002) suggest a definition that includes normative levels of social and occupational functioning, independent living and remission or non-intrusive levels of psychiatric symptoms, in an attempt to reach consensus between researchers, mental health professionals and consumers. The criteria for recovery as suggested by Liberman *et al*. (2002) refer to the past two years of an individual's life and include (a) sustained remission of psychotic symptoms; (b) full or part-time engagement in an instrumental role activity (i.e. worker, student, volunteer) that is constructive and appropriate for culture and age; (c) living independently of supervision by family or other caregivers such that responsibility for day-to-day needs (e.g. self-administration of medication, money management) falls to the individual; and (d) participating in an active friendship and/or peer social relations or being otherwise involved in recreational activities that are age-appropriate and independent of professional supervision.

Following a national conference in 2004, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the US Department of Mental Health and Human Services released a consensus definition of recovery: "a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential" (Substance Abuse and Mental Health Services Administration, 2006, p. 1).

Over the past two decades, with the growing influence of the user movement and a growing amount of literature as well as reports on qualitative studies, different understandings of 'recovery' have developed. These understandings view recovery as *vision*, *process* and/or *outcome* (or set of outcomes indicating a desired end state). The dimensions of process and outcome seem to be widely accepted as a sound distinction (Bellack, 2006). However, the precise definition of both process and outcome is still debated. The notion of recovery as an outcome has been critiqued for not being sufficiently evidence-based (Remmington & Shammi, 2005), lacking a shared operational definition (Liberman & Kopelowicz, 2005) and raising unrealistic expectations (Masland, 2006; Satel, 2006). The notion of recovery as a process has also been criticised. The term 'being in recovery' is being used so broadly and loosely that it borders on becoming meaningless (Lester & Gask, 2006; Roe, Rudnick & Gill, 2007).

Since the notion of recovery originated in the USA, there has been some criticism that this notion heavily focuses on the individual process of recovery, but overlooks the social, cultural, economic and political processes that enable recovery (O'Hagan, 2003). In recent years there has been an increased focus in North-American literature on contextual factors (e.g. Ochocka *et al*., 2005; Onken, Craig, Ridgway, Ralph & Cook, 2007).

2.4 Longitudinal studies

Despite the methodological limitations noted in paragraph 2.2, the longitudinal studies in the seventies and eighties of the last century show quite clearly that many people with a serious mental illness seem to be able to manage their life despite their symptoms, that a certain group becomes completely symptom-free and that many individuals are leading socially integrated lives at follow-up. In Table 2.1 I summarise the most important outcomes of these studies, as reviewed by Harding and Zahniser (1994), followed by the main findings of each study.

Table 2.1: Results of five longitudinal studies on recovery (Harding & Zahniser, 1994)

	No. of subjects	% symptomatically and socially recovered	% socially recovered	total %
Bleuler, 1968, 1978, Switzerland	208	23	43	66
Tsuang, Woolson & Fleming, 1979, Iowa, USA	186	20	26	46
Ciompi 1980a;1980b, Switzerland	289	27	22	49
Huber, Gross, Schuttler & Linz, 1980, Germany	502	26	31	57
Ogawa *et al*., 1987, Japan	140	31	26	57
Harding *et al*., 1987a; 1987b, Vermont, USA	269	34	34	68

Bleuler (1968; 1978) followed the evolution of 208 people diagnosed with schizophrenia. He found that after an average of five years after the diagnosis had been made, the majority of the patients recovered totally or socially. Moreover, the situation of the patients continued to change over a period of several years, in some cases over a period of decades, mostly representing an improvement.

Later, Bleuler summarised how these findings have affected what we know about the course of schizophrenia (Bleuler 1991, p. 5) as follows:

> There is no specific course for the disorder. Instead, the outcomes of schizophrenic psychosis are extremely diverse, varying among prolonged recovery, intermittent course, and prolonged psychosis of severe or mild degrees. For a long time, many psychiatrists believed that a precise definition of the diagnosis indicated a specific prognosis. Experience has shown that no matter how we formulate the diagnosis, it never insures predictable course and outcome.

Ciompi (1980) conducted a study on 289 people with the diagnosis of schizophrenia. The length of time between the first hospitalisation and the end of the study averaged 36.9 years. Although the courses follow different patterns (Ciompi describes eight different patterns), the most common course consists of the sudden onset of the illness followed by a period of intermittent recovery and relapse, and then by an end state where the person has recovered. Ciompi writes as follows (1980, p. 26):

> "The global outcome of schizophrenia, measured at the final state, was favourable in 49% of the cases, of which 27% had totally recovered and 22% had only minor relapses, compared with 27% with unfavourable outcomes of medium and serious degree. In comparison with the situation at first hospital admission, their mental health had totally or partly improved in about two-thirds of the cases."

One-fourth of the people had been hospitalised for 20 years of more, but as many as 47% had been hospitalised for short periods amounting to less than a year. Although the average age of the people was 74 years at the time of the study, over half of them performed work of some kind. Ciompi concludes that only a minority of the patients with a schizophrenia diagnosis developed a course predicted by the criteria of this diagnosis.

Harding and colleagues conducted a follow-up study of a group of 213 patients from a psychiatric hospital in Vermont (USA), which constituted the hospital's residual population of 'severely disturbed chronics', who had been discharged after participation in a comprehensive rehabilitation programme between 1955 and 1965 (Harding *et al*., 1987a; 1987b). A total of 82% had not been hospitalised during the year preceding the follow-up. Forty per cent had a job, 68% showed no or only minor symptoms, while 68% had formed or participated in a supportive social network. The Harding study shows that even for people with a long hospitalisation history, recovery is quite possible, although McGlashan (1988) expressed the criticism that the research group consisted of people who recovered fast from their psychiatric symptoms because they responded well to the new neuroleptics and that after discharge from hospital they were very motivated to find a job because they were poor and did not have the support of relatives or social benefits.

Deegan (2002) reviewed the outcomes of recovery studies in many different forms over the past hundred years and concluded that the recovery percentages did not vary much, despite of changes in economic, social and cultural circumstances and also despite the state of mental health services. This confirms the outcomes of a meta-study conducted by Warner in 1985. Warner (1985) included 87 studies on the recovery of people diagnosed with schizophrenia conducted between 1919 and 1979. The studies were on patients hospitalised between the 1880s and 1970s. The data from the first 10 years were excluded because there were too few studies. The percentage of recovery drops in the period between 1921 and 1940, a time characterised by economic crisis and high unemployment. It rises after 1956, when modern psycho-pharmaceuticals were introduced, and the era of deinstitutionalisation was entered. However, the correlation between recovery rates, societal and mental health variables, and the percentage of discharged patients does not seem strong at all – an exception being that periods with high unemployment coincide with periods when there are few discharges from psychiatric hospitals and few reported cases of social and total recovery.

Table 2.2: Review of longitudinal studies between 1901 and 1980 (Warner, 1985)

Warner (1985)	Number of studies	% of discharges	% totally recovered	% socially recovered	% recovered
1901–1920	12	55%	20 (range 2–30)	40 (range 19–60)	60
1921–1940	25	50%	10 (range 0–23)	30 (range 8–45)	40
1941–1955	17	70%	20 (range 12–41)	40 (range 26–59)	60
1956–1980	29	80%	20 (range 7–52)	40 (range 21–81)	69

Hegarty, Baldessarini, Tohen, Waternaux & Oepen (1994) conducted a meta-analysis of outcome studies in schizophrenia for the years 1895 to 1991, limiting the comparative analysis to 320 studies (of 51 800 subjects) that assessed outcome in less than 10 years to detect trends by decade. The findings show that improvement over an average of six years increased after mid-century, with 35% showing improvement between 1895 and 1955 versus 50% between 1956 and 1985.

Davidson and McGlashan (1997) reviewed studies on course and outcome as of the 1980s. They located nine follow-up studies in Western countries and five cross-cultural studies. In Table 2.3 some results are summarised from the American and Western-European studies.

As in the earlier studies, recent follow-up studies continued to find a broad heterogeneity in long-term outcome in schizophrenia, with 17 to 57% of subjects achieving a good outcome ranging from mild impairment to full recovery. The studies provide further evidence that deterioration occurs within the first few months of onset, followed by a plateau in functioning, which then may or may not be followed by gradual improvement. Affective symptoms and depressive episodes appear to be predictive of a more favourable outcome. Assertive rehabilitation interventions appear to improve long-term outcome, while responsiveness to biological treatments early in the course of illness may be strongly predictive of long-term outcome. Recent studies tend to confirm the finding that early detection and intervention, combined with a good response to psychotropic medication, can favour progressive amelioration (e.g. McGorry, Killackey & Yung, 2008).

Table 2.3: Results of a review of six longitudinal studies between 1991 and 1995 (Davidson & McGlashan, 1997).

	No. of subjects	Findings	% symptomatically and/or socially recovered
Carpenter & Strauss, 1991, USA (11-year follow-up study)	40	Level of functioning in life domain before onset most predictive of outcome; outcome at 2- and 5-year follow-up remains stable at 11-year follow-up.	57%
Helgason, 1990, Iceland (20-year follow-up study with people not hospitalised at the time the study started)	107	20-year follow-up of non-hospitalised patients, with an average delay of 6–7 years between the onset of the illness and first psychiatric contact. Outcome was extremely poor for 21%. Patients who sought treatment earlier in the course of the illness had a more favourable outcome.	33%
Carone *et al*., 1991, USA (young patients)	79	Improvement between 2.5- (10%) and 5-year (17%) follow-up after hospitalisation; decrease of hospitalisation over the years despite persisting symptoms.	17% after 5 years
Breier *et al*., 1991, USA (young patients)	58	More negative symptoms with longer duration of illness; 24% experienced at least one period of major depression; level of symptoms related to functional capacity in social, work and independent living domains. Responsiveness to medication favours good outcome.	21% after 6 years (41% poor outcome; 38% moderate outcome)
DeSisto *et al*., 1995, USA (retrospective study 32 years after discharge from hospital)	180	Comparison of the Vermont study (Harding *et al*., 1987) with a cohort in Maine, USA. Vermont subjects showed better outcomes. Attributed to rehabilitation and community support programmes in Vermont, which were not available in Maine.	49%
Mason *et al*., 1995, UK (13-year follow-up study)	67	97% living independently in the community, 22% employed.	55%

Harrison *et al.* (2001) conducted an international historic prospective review study on recovery from schizophrenia and related psychoses. They combined the data of different World Health Organization (WHO) studies and tried to tackle the methodological problems that have hampered cross-cultural comparisons of course and outcome in the past. The study included more than 1 600 people from over 10 countries in Asia, Europe and North

America. The set of variables chosen was based on a conceptual framework that links environmental, predisposing and clinical factors to outcomes that may mediate their impact.

The conclusion was that a significant proportion achieve favourable long-term outcome. Socio-cultural conditions appear to influence long-term course, although it was difficult to determine the exact nature of these factors. Global outcomes at 15 and 25 years were favourable for over half of all people followed up. Striking heterogeneity was seen across the different dimensions of outcome. A baseline diagnosis of ICD-10 schizophrenia was consistently associated with poorer outcomes in symptoms, social disability and resource utilisation. Despite marked variations across cultural settings, the absolute mortality risk for people with schizophrenia and related psychoses is high and remarkably similar in all the countries examined.

The researchers used Bleuler's typology (Bleuler, 1978) to examine the course and outcomes of recovery 15 and 25 years after onset. Bleuler combines mode of onset (acute versus insidious), overall trajectory (simple versus episodic) and end state (good, meaning recovered or minimal symptomatology versus poor, meaning moderate or severe impairment). Episodic illness accounted for favourable outcomes in well over half of all participants (56% of the incidence cohort and 60% in the prevalence cohort). Evidence of late improvement was shown in 16% and 18% respectively at the 15-year follow-up. The percentage of time spent experiencing psychotic symptoms in the two years following onset was the best predictor of all outcome measures. The shorter the percentage of time with psychotic symptoms, the better the longer-term symptom and disability scores, as well as the overall course of illness.

On average, longitudinal studies show that over the years a greater percentage of people with serious mental illness recover, as is shown in Table 2.4 below.

Table 2.4: Years after hospitalisation and recovery rate

Number of years after hospitalisation	Recovery rate	Authors, year of publication and country in which the study took place
2.5 years	10%	Carone, Harrow & Westermeyer, 1991, USA
5 years	17%	Carone *et al*., 1991, USA
6 years	21%	Breier, Schreiber, Dyer & Pickar, 1991, USA
11 years	57%	Carpenter & Strauss, 1991, USA
13 years	55%	Mason *et al*., 1995, UK
32 years	49%	DeSisto, Harding, McCormick, Ashikaga & Gautum, 1995a;b, USA
32 years	68%	Harding *et al*., 1987b;c, Vermont, USA
37 years	49%	Ciompi 1984, Switzerland

More recent studies show that a combination of efforts after first psychosis may significantly reduce the time needed for symptomatic recovery, thereby also influencing favourable social recovery (e.g. McGorry, Killackey & Yung, 2008). Important factors seem to be the prevention of hospitalisation or the reducing of hospitalisation to the minimum; the organisation of adequate support from the social network; and the provision of good medication, education, counselling and supportive out-patient mental health care services.

The data of the study of Harrison *et al.* (2001) also suggest that early intervention programmes, including both pharmacological measures and psychosocial rehabilitation programmes (such as family psychological education and family support, peer support, illness management, supported education and supported employment), have a favourable impact. These findings are supported by the qualitative studies that are reviewed next.

2.5 Qualitative studies

On the basis of the criteria listed in paragraph 2.2, 28 different qualitative studies were selected, including more than 950 subjects. Most studies are from the USA (14). Three studies are from Scandinavia, two are from the UK, two are from Canada, two are from the Netherlands, two are from New Zealand, one is from Australia and one is from Taiwan. One study is a multisite study using data from four different countries, namely the USA, Norway, Sweden and Italy. In Table 2.5 the studies are listed in chronological order of publication.

I present the data from these studies as follows. First, I start with depicting what happens if someone is faced with a serious mental illness. I use information from a number of studies that illustrate phenomena accompanying a mental breakdown (paragraph 2.6). Then, the results of a comparative analysis are presented, looking at the course of the process (paragraph 2.7) and factors that influence this process (paragraph 2.8). A cluster analysis reveals four clusters of personal factors and one cluster of environmental factors. In paragraph 2.9, I describe the interaction between recovery factors.

Table 2.5: Overview of selected qualitative studies

Authors	Year of publication	Type of study
Hatfield & Lefley, USA	1993	Analysis of autobiographic literature
Sullivan, USA	1994	Open-ended interviews and focus-group discussions (n = 46)
Ralph, Labric & Steele, USA	1996	Focus-group discussions and rating questionnaire (n = 251)
Tooth, Kalyanansundaram & Glover, Australia	1997	Qualitative interviews and focus-group discussions (n = 57)
Baxter & Diehl, USA	1998	Semi-structured interviews (n = 40)
Ralph, USA	2000	Focus-group discussions and analysis of recovery literature
Young & Ensing, USA	1999	Literature research and qualitative interviews (n = 18)
Smith, USA	2000	Qualitative interviews (n = 10)
Ridgway, USA	2001	Analysis of first-person recovery narratives (n = 4)
Torgalsboen, Norway	2001	Qualitative interviews (n = 17)
Topor, Sweden	2001	Qualitative interviews (n = 16)
Boevink *et al*., Netherlands	2002	Focus-group discussions with emphasis on learning from narratives (n = 8)
Spaniol *et al*., USA	2002	4-year follow-up study using in-depth interviewing (n = 12)
Onken, Dumont, Ridgway, Dornan & Ralph, USA	2002	Structured focus-group discussions (n = 115)
Lapsley, Nikora & Black, New Zealand	2002	Qualitative interviews (n = 40)
Tandy, UK	2003	Qualitative interviews (n = 6)
Mancini, USA	2003	Qualitative interviews (n = 15)
Van de Langenberg, Van Orsouw, Prinsen & Jacobs, Netherlands	2004	Focus-group discussions (n = 15)
Cohen, USA	2005	Qualitative interviews and survey (n = 36)
Ochocka *et al*., Canada	2005	Qualitative interviews (n = 28)
Davidson *et al*., USA, Norway, Sweden, Italy	2005	Qualitative interviews (n = 12)
Barnett & Lapsley, New Zealand	2006	Qualitative interviews (n = 40)
Jensen & Wadkins, USA	2007	Qualitative interviews (n = 20)
Brown & Kandirikirira, UK (Scotland)	2007	Qualitative interviews (n = 67)
Judge, Estroff, Perkins & Penn, USA	2008	Qualitative interviews (n = 15)
Borg & Davidson, Norway	2008	Qualitative interviews (n = 13
Song & Shih, Taiwan	2009	Qualitative interviews (n = 15)
Piat *et al*., Canada	2009	Qualitative interviews (n = 54)

2.6 A disrupted life

A serious mental disorder can be caused by different biological, psychological and social factors. It causes numerous serious disturbances with which a person has to deal. Among these disturbances are a disturbed perception; attention deficits; loss of ego boundaries and sense of unreality; disturbed thinking; and disturbances in emotions, relationships and behaviours. Actively seeking and gaining control over psychotic and other psychiatric experiences are important steps in the recovery process.

The impact of mental health problems on people's social lives is often highly disruptive, and includes the disruption of relationships with partners, children, parents and friends. Many people report severe impacts on their career or potential career. In addition, stigmatisation is a major problem.

Strauss (1989a) describes psychosis as the breakdown of the self's way to deal with reality, either as a result of internal conflicts, biological tension or stress generated by external sources. He describes a course of development that corresponds with the three phases of a psychotic breakdown. People who have entered the first phase experience mounting stress caused by an inappropriate way of coping with their overall situation. As the tension rises, they become increasingly rigid in their way of handling their situation. This in turn leads to even greater stress and finally to a psychotic breakdown. Psychosis is defined by Strauss as the disorganisation of the self. This may lead to a reorganisation to enable it to function more flexibly, but also 'stuckness' may result. Recovery generally requires the self to be reorganised in a new way, which Young and Ensing (1999, p. 5) call "overcoming stuckness".

Hatfield and Lefley (1993) performed an analysis of first-person accounts of how people themselves experience disturbances caused by a mental breakdown and the way they cope with it. They distinguish three types of disturbances: disturbances in the sense of self; disturbances in cognition; and disturbances in emotions, relationships and behaviours. I will use this typology to describe what is happening to the person experiencing a mental breakdown.

Disturbances in the sense of self

The first cluster is about disturbances in the sense of self. Disturbances in the sense of self have the following different elements:

- A disturbed perception is a primary factor. People suffering from psychosis experience a wide range of perceptual distortions. The perceptual world may be flooded with images that they cannot control. They may experience significant changes in intensity of stimuli, things may look strange and unreal, and objects may change in size and shape. There may be abnormal time and space perceptions, distortions of bodily sensations, and changes in the perception of emotions. People with psychosis suffer from high levels of stress and anxiety as they strive to negotiate with the world of their inner experience and the world they share with others. When their perceptions go awry, they lose the sense of environmental stability that would allow them to function with comfort and confidence. They lack the capacity to organise perceptions to manageable proportions.

- A disorder of attention is another category often mentioned by people with psychotic impairments. Freedman (1974) studied over 50 autobiographical books and articles and noted that over half of them reported problems in concentrating on reading, writing and speaking, or that the minds of the authors wandered a great deal. One explanation for this is that people have difficulty in filtering out irrelevant details and controlling that to which they will attend (Freedman, 1974; Torrey, 1983). It is as if the brain is flooded with both internal and external stimuli. There seems to be a problem with information selection. People report a sensation of being captured by a stimulus rather than being able to choose what to attend to. Minor factors (e.g. colours, textures or blemishes) attract these people with a salience out of proportion of its importance. People cannot shift their attention flexibly because they lack the capacity for control (Anscombe, 1987). A coping mechanism of this attentional deficit is to withdraw into passivity.
- Psychotic experiences lead to a loss of ego boundaries and sense of unreality. Estroff (1989) regards the loss of the sense of self as central to schizophrenia. The illness tends to encompass the identity of the person. A number of first-person accounts studied by Hatfield and Lefley (1993) seem to confirm this (King-Hasher, 1989; Landis & Mettler, 1964; McGrath, 1984; Sharp, 1987). The environment often tends to confirm the loss of self. Family members distinguish between the person they knew before he or she became ill and the person afterwards. The struggle for the self goes on both privately and publicly, both in terms of the inner sense of self and in terms of social identity.
- Besides a loss of the self, an altered sense of self can also take form in dissociation of body parts, believing another person or creature is taking over control, or believing that the person is in fact another person, such as Jesus Christ (Frese, 1993; Torrey, 1983; Zelt, 1989).

The personal significance of psychotic experience is not always regarded as bad. Some people attribute great meaningfulness to the phenomena they experience, as evident in accounts of 'feeling special'. Some people feel that voices they heard provided company to them and protected them from feeling lonely. Some people state that psychotic experiences helped them in their recovery process, as indicated in the following excerpt:

> My first psychotic episode appeared as a private mental exorcism, ending with the honour of sainthood and gifts of hope and faith. Fortunately, this sense of power became a tremendous strength during my recovery and sustains me even today (Houghton, 1982, p. 549)

Topor (2001) concludes that the lost of the sense of self has often occurred (long) before a psychiatric diagnosis was made. The process of self-alienation is in many stories induced by a growing sense of inferiority, sometimes caused by circumstances in the childhood not permitting the development of a person with sufficient basic self-confidence (such as a suppressing parental regime or traumatic events). This is confirmed by my own study (see Chapter 3).

In the process of coping with alienation and feelings of inferiority, a number of strategies come to the fore, which can be divided into two main categories: hiding the inferior self,

sometimes by dissociation, or exposing it by attention-seeking behaviour. Recovery implies trying to connect the different parts in a way to ensure that they can be controlled and experienced as 'this is me'.

Hatfield and Lefley (1993) emphasise the need to study the processes and experiences of change, loss and persistence of the self accompanying psychotic disorders. Actively seeking and gaining control over psychotic experiences are important steps in recovery. Hatfield and Lefley speak of becoming an "active agent" (1993, p. 125). One person who has written extensively about this process is Leete (1989, p. 198-199), who says "I have become an expert in my illness" and "'I have learned coping mechanisms". Keil (1984) found that she could learn to control her words and actions even if she was unable to control her racing thoughts. People obviously have the capacity to adapt – separating parts they cannot control from parts they can and thereby avoiding total paralysis. Being stimulated by strong motivation is reported to be an important factor in making a change (Savelson, 1986). Part of the self-image is whether someone regards him- or herself as a victim and is unable to change this. This image is often evoked by the environment (as in utterances such as "This is an incurable disease" and "There is nothing to be done about it").

Strauss has written extensively about these person–disorder interactions (Strauss, 1987; 1989a; 1989b; Strauss, Böker & Brenner, 1987). In Strauss's experience, people consciously or unconsciously appear to adjust their perceptions, interpretations and actions to maintain a level of self-esteem, they remain on plateaus of development in order to recuperate and they use footholds in one aspect of life before taking another step.

Disturbances in cognition

The second cluster deals with disturbances in cognition. In a number of studies, people's statements about coping with cognitive problems are described (Freedman, 1974; Kaplan, 1964; Leete, 1987a; 1989; 1993; Torrey, 1983). Disturbances in cognition include

- racing thoughts and stimulus overload;
- yielding to associative connections;
- slowed thoughts and mental blocking; and
- disturbances in judgement and reasoning.

It is clear that these disturbances seriously affect all aspects of living, including the sense of self and the ability to exert control over these disturbances. What is encouraging is that many people speak of making efforts to manage these informational deficits and of developing strategies whereby they can go on with their life. Many different coping strategies are reported. One of the most frequently used coping strategy is that of creating a certain structure for themselves, which can control disturbing thoughts, or of finding or entering a structured environment that is less stressful.

Disturbances in emotions, relationships and behaviours

The third cluster includes disturbances in emotions, relationships and behaviours. People diagnosed with schizophrenia report suffering highly disabling emotional experiences, such as fear, anxiety, depression and guilt. In addition, physical pains are reported. Sometimes they experience the opposite, with little or no feeling at all. Disturbances of the self and cognitive deficits, such as a decreased empathic ability, can lead to a number of problems in

engaging in and maintaining relationships. It seems that the more attention internal stress management requires, the less energy can be spent on relationships. This may lead to isolation and loneliness. Another factor is the sensitivity to the emotions and behaviours of others. Verbal and non-verbal communication can easily be misinterpreted, and avoidance can be the consequence. Finally, a number of interpersonal behaviours are mentioned, which can be a burden for the person as well as for the environment, such as excessive smoking, eating and sleeping and self-destructive behaviour.

Origins

In the study by Lapsley *et al.* (2002), conducted in New Zealand, for most participants aspects of the past contributed to the mental health problems they experienced as adults. A few described family legacies, but most references were to circumstances or events from childhood or adolescence that they associated with their mental ill health later in life. The three major themes identified as childhood contributors to mental health problems later in life were the following:

- Abuse (physical and/or sexual, mainly within the family, but also at school)
- Loss and abandonment (mainly in relation to parents, due to separation or death, lack of parental warmth, or feelings of abandonment)
- Feeling different (especially in relation to other children, because of factors such as illness, disability, sexuality, educational failure or ethnicity)

For many participants 'there was always something the matter' in terms of their mental health. For quite a number of participants, some symptoms of mental ill health manifested during childhood, but these were seldom investigated. Stories about the onset of a mental health problem usually entailed stressful circumstances becoming increasingly difficult to bear. During this time it was common for a critical incident to occur, acting as the last straw and precipitating a mental health crisis. The shape of 'onset stories' was: "I found myself in a difficult situation, something very stressful occurred and I just could not cope any more". Reviewing the circumstances that were mentioned as stressful, the following central themes can be identified:

- Isolation, loneliness and lack of support (from wider social networks, after partnership breakdown, or because of illness and unemployment)
- Loss (partnership breakdown, loss of family support, bereavement, loss of job, loss of health)
- Identity conflicts (including sexual identity, work identity, transition to adulthood)
- Responsibilities that were too demanding (at work, parenting) (reported less frequently)

Although some participants described their mental health problem as developing gradually against a background of stressful circumstances, many could point to an upsetting event that served as a 'last straw'. For some it was an incident, such as a suicide attempt, which made it clear to themselves (and to others) that they were in a crisis situation. The critical incident often precipitated hospitalisation. The most frequently described critical incidents were those that provoked a devastating sense of shame, humiliation or failure, which then triggered the mental health problem. This is shown in the next example.

> Hare's kuia [Maori word for mother – JPW] died and everything went wrong for him. He took to selling drugs, and the voices that had been with him since childhood

became more troublesome. When someone accused him of killing her brother, who had died of a drug overdose, he 'lost it': "Everything just went black and next thing I'm tripping out in the psych ward" (in Lapsley *et al*, 2002, p 22).

Other critical events included reactivation of an earlier trauma, physical health problems or losing control over one's life.

Struggling with the illness

Having a mental health problem involves experiencing symptoms of mental ill health and, usually, encounters with the health system, whether it be primary health care or specialised mental health services, for diagnosis and treatment. The characteristic 'story' for this phase of the journey was: "The mental health problem took over my life". Mental ill health experiences, with all their disruptions to normal states of mind, body and wellbeing, had a strong impact on people. Fear was the predominant reaction, and lacking an understanding of the problem added to this fear, as evident in the following excerpt.

> "I just wasn't coping, you know, with normal things and the more I couldn't cope with normal things, the more I got frightened. Because I did not understand what was going on." (Denis, as cited in Lapsley *et al*., 2002, p. 27).

People used different strategies to cope with this situation, such as withdrawal, as was the case in the following excerpts:

> "'I tried to help myself. I stayed in solitary for six months ... in a motel room."

> "I wasn't feeling [like] myself, and things were strange, and I guess I was reluctant to tell people. It was kind of outrageous what was going on, and it was hard to put into words because it was so complicated ... so I did pull back." (Citations from the narratives collected by Judge *et al.,* 2008, p. 98)

Not knowing how long these distressing states would continue was distressing in itself, and for those who were troubled by suicidal thoughts, the lack of a time perspective made matters worse. Fear of 'going crazy' was also a concern for some, with 'crazy' representing a frightening, out-of-control and possibly permanent state even worse than the one being experienced. Confusion was another common reaction, especially for those who experienced more intensely unusual states of mind, such as psychoses. Example:

> "I was so totally confused about everything that went on, I mean, I didn't know what was happening to me, I was in shock." (Cathy, cited in Lapsley *et al*., 2002, p. 28)

The early stages in the processes of recovery becoming evident from the narrative studies are marked by a struggle with the mental illness. The study by Davidson *et al*. (2005), conducted in four countries, provides a number of examples, such as the following:

> "I didn't accept myself but I didn't know what I should do to get better." (Davidson *et al*., 2005, p. 183)

People were confronted by phenomena inside themselves that were unfamiliar to them and had to find a way to deal with it. Davison *et al*. (2005, p. 184) describe this situation as follows:

> "Participants were unprepared for the onslaught of psychosis and initially had no idea of what to do or how to survive, not to say manage, these new experiences. They were aware of no longer being 'themselves' to whatever degree, but also had no idea of how to return from whence they came or where they could turn for help."

The important task in this early phase is to tame the psychosis: finding ways to understand and to minimise the intrusions and disruptions brought about by psychosis. This is not easy since there is no frame of reference (either previous experiences or information) to hold on to. This is shown in the example of Ole:

> "It took several years before I realized that this is something you have to work with and really have a conscious relationship to because in the beginning I guess I thought that this is sort of like breaking a leg. I thought it would take two or three years and then it would pass and it wasn't like that. It took some time for me to realize that." (Ole, cited in Davidson *et al*., 2005, p. 184)

Interaction with the community

The impact of mental health problems on people's lives is often highly disruptive. Part of the recovery process involves coming to terms with these disruptions and, for many, beginning over again. Reported disruptions are relationships with partners, children, parents and friends. Many people speak about severe impacts on their career or potential career.

Being socially stigmatised is a pervasive consequence of mental ill health. Mancini (2003, p. 65) speaks of an "illness-dominated identity". In the accounts, experiences with mental health services, and the impact of mental ill health on family, friends and career, stigma and discrimination often feature. Stigma has an internal shape, too. Many participants were ashamed that they had become mentally unwell, especially if they were marked out by having spent time in hospital. Shame lowered self-esteem and impeded recovery. One participant remarked on this as follows:

> "'I was convinced that people could tell just by looking at me. It was like I had a band across my forehead saying 'been to Tokanui' ... Each time I'd come back into the community with more and more stigma … attached to me." (Kim, cited in Lapsley *et al*., 2002, p. 42)

In the interaction with the environment, people report stimulating and hindering factors. Psychiatric hospitals are regarded, as was especially the case by consumers in the seventies and eighties, as restricting and dehumanising places. People are treated as abnormal and infantile, not being able to speak for themselves. Staff use 'technical' language, speaking in medical terms.

> Judy Chamberlin is one of the persons who has prominently described the demeaning and restrictive aspects of hospitalisation: "The whole experience of mental hospitalization promotes weakness and dependency. Not only are the

lives of patients controlled, but patients are constantly told that such control is for their own good" (1978, p. 6). Chamberlin writes that, as a reaction, this strips people of self-esteem and decision-making capabilities: "Patients become unable to trust their own judgment, become indecisive, overly submissive to authority, frightened of the outside world".

On the other hand, a number of people also report positive feelings towards psychiatric hospitals, as they provide a safe haven, a place where experimentation with medication can take place, and where evaluations can be made about what has happened in crisis situations.

Stigma

In the community, stigma is regarded as the most critical burden suffered by people with serious mental illnesses, and a major obstacle for recovery (Link, Phelan, Bresnahan, Stueve and Pescosolido, 1999).

There are many different aspects of stigma, of which a few are the following:

- People may be regarded as dangerous or lazy; this leads to problems getting or maintaining housing and work.
- Estroff (1981) wrote about the double binds built into the mental health system. Recovery is regarded by the system as a linear process in which mentally ill people are expected to follow a straight path of improvement to independent living. The cyclical nature of bipolar illness and the ups and downs of schizophrenia are not taken into account, and neither are the physical limitations of people who cannot cope with undue stress and high-demand environments. This view leads for example to a loss of social benefits, since people in recovery are expected to work again, and not to have a vulnerability that can lead to a setback.
- People may have internalised the stigma attached to having a mental illness or being hospitalised (Campbell, 1989; Estroff, 1989). From research conducted by Link (1991), it is clear that there is a relationship between the degree to which people expect devaluation and discrimination, and the degree to which they are employed and have social support. Link concludes: "The uncertainty, tentativeness, and withdrawal that can result may affect performance in the job market, social network ties, and a patient's view of himself/herself" (1991, p. 5).
- A general way in which stigmatisation occurs is that people are judged by their appearance, manner of speaking, occupational role and ascribed status in life. Once people reveal that they have a disability, there is an immediate danger of being stigmatised. No wonder that people often try to hide their psychiatric background. The consumer movement is often a good vehicle to 'come out', to build self-esteem, to fight stigma and to advocate for citizens' rights.

2.7 The process of recovery

A number of authors have described the course of a recovery process (Andresen, Oades & Caputi, 2003; Forbess, 1993; Lapsley *et al*., 2002; Ochocka *et al*., 2005; Spaniol *et al*., 2002; Strauss *et al*., 1985; Wilken & Den Hollander, 1999; Young & Ensing, 1999).[7]

An overview of these studies is given in Table 2.6.

Table 2.6: Phases in the recovery process coming to the fore from different studies

Author(s)	Phases			
Strauss et al., 1985	Moratorium	Convalescence	Reconstruction	
Forbess, 1993; Wilken & Den Hollander, 1999	crisis - disintegration	Stabilisation	Re-orientation	Re-integration
Young & Ensing, 1999		Initiating phase: initiating recovery	Middle phase: regaining what is lost and moving forward	Later phase: improving quality of life
Spaniol et al., 2002	Overwhelmed by the disability	Struggling with the disability	Living with the disability	Living beyond the disability
Lapsley et al., 2002		glimpses of recovery		turning point and road to recovery
Andresen et al., 2003	Moratorium	Awareness Preparation	Rebuilding	Growth
Ochocka et al., 2005		Awakenings or turning points: motivation to 'move forward'		Dialectic process of 'negotiating self and external circumstances'

When comparing the different phase models, it becomes clear that all models describe a developmental process from the onset of the illness, often accompanied by a state of serious crisis and disintegration of the self, leading either to a state in which the person knows how to cope with the illness and its consequences or to a total recovery (defined as the absence of the illness). During this process, two parallel processes evolve: a process in which the person has to come to terms with him- or herself, and a process of reconnecting to the world.

Reconnection is a word that describes well the focus of both processes. These people have to re-connect to themselves, find their core identity and take control over their disability and their own life. They also have to re-connect to the world around them: their social network, the school, the neighbourhood, the job. Establishing this reconnection requires personal strengths, and (re)discovering these strengths in a continuing process of self-empowerment seems to be a golden thread in the phases of struggling with the disability and overcoming the consequences.

[7] All studies but the Ochocka study have been reviewed in Wilken and Den Hollander (2005, p. 35–58).

In response to the question "Recovery from what?", a multi-level, contextual analysis conducted by Ochocka *et al*. (2005) illustrates that there is recovery from serious mental illnesses; recovery of a positive sense of self; restoration of damaged relationships or the development of new, more positive relationships; and reclaiming of human and social rights, as well as a place in the community. Recovery occurs across a number of areas. People need to recover from

- *what has been the matter in the past (and still forms an impediment)* (such as family legacies; childhood losses, disruptions and trauma; feelings of difference);
- *stressful situations that led to the onset* – or identification – of the mental health problem in adulthood;
- s*ymptoms of mental ill health,* which, for most people, no matter how their problem was named, involved disturbance across a wide range of personal functioning;
- *fears and anxieties* surrounding the symptoms and their possible recurrence;
- *treatments* received for the problem, some of which were unpleasant, frightening and even traumatising (especially those involving hospitalisation, drugs, Electric Convulsive Treatment);
- *consequences* of the mental health problem and also of its treatment, which often involve major disruptions in personal relationships, employment and education, and could lead to isolation, joblessness and poverty;
- *destruction of self-esteem* with the lost of trust, optimism, hope and faith in the future; or
- *stigma* associated with mental ill health, experienced within oneself as shame and from other people as social exclusion and discrimination. (Lapsley *et al.*, 2002)

In the process of recovery there is a line going from being disrupted, disconnected and disintegrated to being connected and integrated. In this process the person tries to come to terms with the illness and its consequences. I use the terminology of the International Classification of Human Functioning (ICF) as developed by the WHO (World Health Organization, 2001). The ICF defines three possible consequences of a biological disorder: changes in physiological or psychological functions or structures, in activity patterns, and in participation in social life. Activity limitations are related to exercising skills and using resources. Participation restrictions refer to fulfilling social roles and participating in community life. Being confronted with a serious mental illness often causes serious problems in all three areas, because they are so interconnected. A difference between psychiatric disorders and other disorders is that the cognitive functions themselves are part of the impairments. Therefore, individuals have to use an impaired cognitive system to repair or to cope with the same system. This requires a great competence of *resilience* and *adaptation*. One of the most fascinating aspects of recovery is that many people apparently succeed to accomplish what seems virtually paradoxical or a 'mission impossible'. The person not only has to cope with his or her illness and the consequent disability, but also with a *history* of disruption, hospitalisation and being cut off from the own trusted self, social relations and social roles. Understanding what has happened, mourning about what has been lost and to some extent being able to accept things as they have occurred are important aspects of the phase of reorientation. "First regain and then move forward", as aptly put by Young and Ensing (1999, p. 225).

Recovery can be defined as a developmental process that can be described on a continuum from disintegration to integration, or from being disconnected to being connected. Integration and connection are related to two entities: the person or the self and the environment or community. In the course of this process, the focus is gradually shifting from the person to the environment.

Although the authors listed in Table 2.6 use different classifications and labels, generally speaking, the actual recovery process entails three phases. In the first phase, the main task is to gain control over the illness itself (disease management). In the second phase, an important task is to develop an explanatory framework for understanding the experience of an illness and to develop a positive future perspective. The person resolves to start working on psychological recovery. This stage involves taking stock of the intact self, and of one's values, strengths and weaknesses. It may involve learning about mental illness, services available or recovery skills, or becoming involved in groups and connecting with peers. The person works to build a positive identity. This involves setting and working towards personally valued goals, and may involve reassessing old goals and values. This stage involves taking responsibility for managing the illness and taking control of one's life. It involves taking risks, suffering setbacks and coming back to try again. This is the preparation for the third phase. In the third phase, the person moves into roles that are meaningful, productive and valued by the larger society. (Wilken & Den Hollander, 1999). The different phases and transitions are summarised in the next table.

Table 2.7: Phases and transitions in the recovery process

1. Stabilisation Disintegration/disconnection from the self and community → stabilisation/reconnection to the self on a basic level of functioning	**2. Reorientation** Reorientation/reconnection to the self on a psychological level → reorientation to the community	**3. Reintegration** Reintegration/reconnection on a social level → connection to the community → integration
Focus: controlling symptoms and diminishing the suffering	Focus: exploring the implications of the illness for the near future; exploring how to get back to a normal life	Focus: restoring meaningful activities, relationships and social roles

From crisis to stabilisation

When a crisis occurs, there is loss of control and disintegration. A person's life falls apart. All social roles grind to a halt until only the role of patient remains. All attention is focussed on combating the illness and the person becomes highly dependent on the expertise of medical practitioners. Hospitalisation, if it occurs, places the person in an alien environment with its own regulations and procedures. This may result in confusion or even mental shock. Bury (1982, p.167) describes this life event as an "acute biographical disruption". Spaniol *et al*. (2002, p. 328) call this being "overwhelmed by the disability". Strauss, Hafez, Lieberman & Harding (1985, p. 291) and Andresen *et al*. (2003, p. 11) call this "moratorium". Young and

Ensing (1999, p. 219) mention that someone has to overcome the "stuckness" in which he or she is trapped. This phenomenon is illustrated in the next example:

> "The beginning of recovery is a total stripping, emotionally and physically. We seem to lose our possessions and lose our relationships and lose – challenge and lose – ... our notions of traditional success." (Alain, cited in Lapsley *et al.*, 2002, p. 47)

Accepting treatment can be difficult, as it requires a certain level of submission that may reinforce the feeling of having lost control. As the person's medical psychiatric condition stabilises, the psychological condition usually improves as well, enabling the return to basic functioning and reflection. Young and Ensing (1999, p. 225) describe this as "regaining what is lost and moving forward", which includes returning to basic functioning, learning and self-redefinition, and discovering and fostering self-empowerment.

A process of returning to basic functioning

A first dimension of the process is that, as people begin to recover, they report becoming increasingly able to take responsibility for their own self-care, such as maintaining proper hygiene and establishing a routine that includes eating and sleeping on a regular basis. Another theme in relation to self-care is complying with a consistent medication regimen. Taking care of one's own living environment is also regarded as being able to live as a capable human being.

Many people report that the most effective way to prevent their illness from taking all their energy and time is to engage in various adaptive activities, which not only divert energy away from their illness but also tend to yield other positive outcomes such as an increased sense of self-efficacy or an enhanced sense of wellbeing. The activities that were most frequently mentioned by participants include exercising, participating in vocational activities such as volunteering and working, and participating in various mental health programmes.

Another aspect of basic functioning is the ability to form meaningful relationships with others. Given the presence of stigma and the fragile sense of self-worth that is experienced by many people, the task of connecting with others can be particularly challenging:

> "I needed to be able to relate to other people what I felt – why I felt so stigmatized by my illness that I couldn't relate to anybody. I felt very alone and very lonely." (Cited in Young & Ensing, 1999, p. 228)

A process of learning and self-redefinition

A second dimension of recovery, as described by Young and Ensing and others, entails the process of learning new perspectives about oneself, one's illness and the world. This happens especially from the second phase onwards, when reorientation starts. Once people develop attitudes and behaviours that produce positive change, they often engage in an exploration of both their internal and external worlds. Mental illness often shatters the core sense of self that was present in the premorbid condition. To overcome this trauma, a new sense of self has to be reconstructed; a self that also has to fit somehow in the external world. After reaching a point where people are stable enough, some sort of internal inventory is performed to find out what parts of the self remained intact. As time passes and

recovery evolves, people often rediscover parts of themselves that they had assumed were lost. However, it is remarkable that in this process, people also discover new potentials, which lead to unexpected possibilities for growth and development. This is illustrated in the next quote:

> "'I'll have to deal and explain my disability and I probably shouldn't sometimes, but to me I feel it's given me a stronger sense of who I am as a person, and I am me instead of a person living with a disability. You are a 100 steps ahead, if you admit that you have a problem and are honest about it." (Cited in Jensen & Wadkins, 2007, p. 332)

New insights are also gained into the relationships between the self and illness. People tend to reconstruct a stable sense of self that incorporates illness as only one aspect of a complex, multidimensional self. It appears that people's sense of self-identity gradually expands, allowing them to place their illness in a new perspective. It often means moving away from the illness identity towards 'being a person with multiple qualities and also some disabilities'. Jacobson and Greenley (2001) prefer the term 'healing' to 'recovery'. They propose that this notion captures a process with two components: defining a self apart from illness, and control.

Many people also report gaining new insights into life in general and living in the world. This includes having social relationships with others, learning what you need from various resources, and learning that there are many productive ways to use time and energy.

Discovering and fostering self-empowerment

For substantial positive change to occur, people noted the need to develop a sense of self-empowerment. This is a third dimension of recovery. A particularly important aspect of self-empowerment is the willingness to take control of one's life by shedding the role of victim in exchange for a new attitude of personal responsibility and self-efficacy. Another important part of taking control is assuming responsibility for the recovery process rather than leaving it up to professionals and caregivers. As people recognised the amount of control they had over their illness, self-empowerment and personal progress appeared to develop.

A particularly salient aspect of the recovery process is to learn how to use self-monitoring and proactive strategies to prevent relapse. Once people learned to recognise their own unique relapse indicators, they developed preventative or proactive strategies to reduce stress or to avoid becoming depressed.

Another part of taking control of one's own life is to take responsibility for one's own behaviours and problems. For some this represented a maturing process that resulted in a willingness to deal with problems rather than denying them or running away. For others it meant recognising destructive behaviours and habits and then making a commitment to reduce or discontinue them. The central aspect of this process is honest self-scrutiny, which results in the recognition of self-defeating behaviours and a commitment towards growth and self-accountability. This is illustrated in the next example.

> "My recovery process began 2 years ago when I took responsibility for me, and I recognize my behaviour and I try to make it a point to kind of look at myself very

objectively… like an outsider and recognize what I am doing. If I don't recognize it I'm never going to stop it or change it." (Cited in Young & Ensing, 1999, p. 226)

Another important aspect of self-empowerment is the process of learning to believe in oneself and strengthening self-confidence. Finally, determination and hard work are two more elements mentioned by many studies. Especially in periods of relapse it requires great effort to go on.

Restoration

In the third phase, re-integration occurs at three levels: the personal level, the inter-personal level and the community level. Communication with the outside world is restored. People set their first steps on the rocky road of learning to live with a new perspective. The person is at the centre of his or her own recovery process, but support from others is still crucial. Slowly, the person's self-esteem grows and coping skills are practised and reinforced. Social contacts are established and a daily routine takes shape. All of this leads to increased independence and competence.

After basic needs are met, people will strive to seek out a new sense of purpose at a higher level of functioning. These are all aspects of increasing the quality of life. They desire a more meaningful existence, looking for work and education opportunities. Another aspect of quality of life connected to this is having enough money to be able to afford a reasonable standard of living and engage in enjoyable activities. A lack of money or a decent place to live were also mentioned as important obstacles in the recovery process in the former phases. Being able to attain a greater degree of independence and self-sufficiency is also a common goal in this phase. As people experience recovery, they often reach a point where they must take a risky decision about whether or not to begin to pull away from mental health services.

People strive to attain an overall sense of wellbeing and to reach new potentials of higher functioning. At this stage of recovery, people reported feeling healthy enough to strive for ideals that are often associated with stable psychological health and self-actualisation. One of the common goals mentioned is simply to feel better about themselves on a consistent basis, feeling normal and feeling stable. There is desire to build a self-image that is adaptive and positive. Experiencing calmness and inner peace becomes a highly valued aspect of the recovery process. Attaining a state of wellbeing includes increasing self-esteem, feeling stable, feeling normal, feeling at peace, caring about things versus being apathetic and adopting more functional thinking patterns. On the basis of a state of wellbeing, people strive for purposeful social (re)integration and to have meaningful social roles and become more self-sufficient. One of the challenges here is coping with the stigma attached to a psychiatric history.

Spaniol *et al*. (2002, p. 331) distinguish two possible variants in the third phase of recovery. The first is "living with the disability" and the second "living beyond the disability". In the first variant, the person feels confident about managing the disability and having some control over his or her life. He or she has discovered that a satisfying life is possible despite having a disability. The person knows how to use effective coping strategies to deal with the impairments and assumes a number of meaningful roles. People can also move 'beyond' the

disability. Then, the impairments and disabilities do not significantly interfere with having a satisfying life. The person feels well connected to the self, to others, to various living, learning and working environments, and experiences a sense of meaning and purpose in life (Blanch, Fisher, Tucker, Walsh & Chassman, 1993; Stocks, 1995; Weingarten, 1994). In this phase, recovery according to the criteria of Liberman *et al*. (2002) is attained (paragraph 2.3).

Recovery as a dynamic and dialectical process

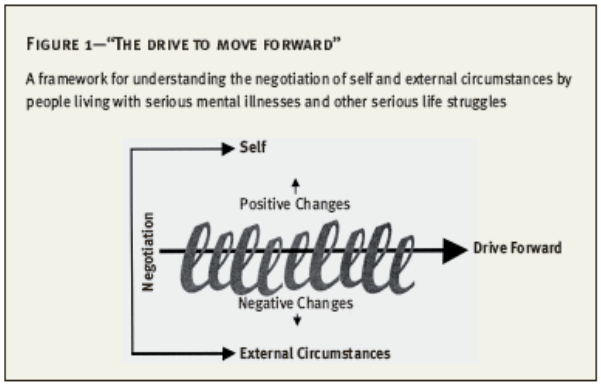
All studies acknowledge the fact that 'the way back' or 'the road to recovery' is not a linear process. The boundaries between phases are not precise and there is a movement within and between phases. The pace of the recovery process can differ from person to person. Some studies show a fast recovery (within one to two years); others a slow recovery (taking decades). Within an individual process, at some time there is some standstill (moratorium); at another time there is fast progression.

Recovery is a dynamic and dialectical process. Each individual continually tries to make sense of and respond to the dual realities of what is going on inside him or her and the external circumstances within which he or she lives. Ochocka *et al*. (2005, p. 315) call this "a process of negotiation". By negotiation they mean "the dialectic process by which each individual continually tries to make sense of and respond to the dual realities of what is going on inside of him/herself, and the external circumstances within which he/she lives". The process of negotiation is ongoing and each person plays a central role as an agent or broker. Such a negotiation can provide a sense of control over life and allows people to overcome and even thrive despite struggles.

The process of negotiation is different for every person and it is often disordered. This element of disorder highlights the fact that a mixture of personal, social and cultural barriers, together with existing relationships, experiences, knowledge and perspectives, combined with living situations to make up the field of negotiation between inner conditions and external circumstances. The outcome of each negotiation can contribute to positive or negative changes, which further add to life experiences, and influence the results of future negotiations. The main components of this recovery framework include the *drive to move forward* (intrinsic life motivation) and the *spiral of life struggle* that results in positive and negative changes (life changes). These life changes demonstrate the outcomes of recovery, which are grounded in the context of the *self and external circumstances* (life context).

The recovery process is ongoing (motivated by a drive to 'move forward'); is non-linear, including both successes (positive changes) and setbacks (negative changes); and is ecologically oriented (lived within the context of the self and external circumstances).
This is depicted in the next figure.

Figure 2.1: The dynamics of a recovery process, reproduced from Ochocka *et al*. (2005, p. 317)



In most studies it materialises that recovery is a process that is quite complex. Central themes in this process are growth and control. People want to progress, but at the same time they want to remain stable and control their vulnerability. Spaniol *et al.* (2002) state:

> When options and opportunities were available, and they made a move, such as out of day treatment, into a clubhouse, back to work, or into a more desirable living situation, participants seemed to experience a period of increased energy and activity. However, growth also brought periods of instability and increased vulnerability. (Spaniol *et al*., 2002, p. 334)

Transitions

In the recovery process, the term 'change point', as used by Strauss, or 'turning point', as used by other authors, is an important notion for marking developments or advances. These points are marked by more or less identifiable events, which, if identified in the narrative of the individual, may form, by the very value of awareness of these events, a new context for striving for new change points. Turning points or change points can be seen as stages in time in which a person switches from a passive, receptive mode to an active mode or from one level of functioning to another level.

I prefer to use the broader notion of *transition*, because most narrative studies show that during a certain period change occurs. This change can be marked by a certain clear point, but often consists of, or is often preceded by, a number of factors. For example, the transition in the first phase of despair to physical and mental stabilisation can mark a first glimmer of hope of a better life, and the realisation that recovery is possible. This can be caused by an internal event, or it can be sparked by a caregiver, significant other or a role-model. It involves an awareness of a possible self other than that of a 'sick person': a self that is capable of recovery.

In the studies different types of transitions are apparent. The first type is the transition at 'rock bottom', or what Rakfeldt and Strauss (1989, p. 33) also call the "low turning point", when people decide that this situation is no longer liveable and has to change. In many

studies it is shown that the starting point of recovery is often a situation of great despair. Often, when a personal crisis is at its peak, people feel an urge for survival and a desire to change the current situation. People develop a feeling that they simply *could not* continue their journey further into mental ill health. "They start to sense something within themselves that made itself known in the worst of despair – some survival instinct, stubbornness, or glimmer of hope" (Lapsley *et al*., 2002, p. 47). Or they decide to live rather than die or wither away in a mental hospital. This transition point is often marked by resistance against oppressive social structures and processes.

People often refer to getting started on the road to recovery as *awakenings* (called "glimpses of recovery" by Lapsley *et al*. (2002, p. 47), or "awareness" by Andresen *et al*. (2003, p. 11). They become aware of their situation, which provides motivation to move forward, sometimes preceded by a period of depression and bereavement.

A study by Barnett and Lapsley (2006) among young people up to the age of 29 in the early stages of their recovery process revealed a second type of transition. In many of the stories in this study, a transition was made when people entered a comprehensive treatment and rehabilitation programme. Here a lot of 'recovery work' is done, which leads to gradual changes over the course of time. The study shows that when it is not yet possible to tell the 'full recovery story' in retrospective, an important factor to move forward is being able to *articulate* and *move towards* the realisation of hopes and dreams.[8]

A third type of transition is marked by (an increasing) *sense of agency.* This refers to the moment people take charge of their illness, their recovery process, or their life in general. This is often accompanied or preceded by insight or self-acceptance. Some studies speak about a kind of religious or spiritual experience. Interventions from others are also mentioned as incentives for change, for instance the belief of a caregiver a relative or a peer that recovery is possible. People experience personal resilience or strengths to undertake some kind of action. This transition is marked by *active acceptance* and taking responsibility for one's own life. Having a (mental) illness can easily mean that people submit themselves to doctors and other carers. It can create a sense of helplessness. Taking responsibility for themselves once again seems to be a great step forward.

The fourth type of transition is further on in the process, when people seem to have adjusted to the disability to a degree that they feel strong enough to make a *change in one of the social domains* of living, work, education or relationships.

Strauss and Carpenter (1977, p. 16) report a phenomenon that they call "mountain climbing". There are several different processes occurring simultaneously and operating as open-linked systems. Strauss and Carpenter mention symptoms, social relations functioning and occupational functioning as such systems, which are relatively independent of each other while also having some intercorrelation. In reviewing the evolution of disorder and recovery, it appeared that people used the achievements in one area, such as social

[8] In the study of Barnett and Lapsley (2006), three subgroups emerge as relatively distinct. The first group consists of the people who are still 'surviving day to day'. The second group consists of those who are taking some concrete steps to achieve their more immediate goals, but who are still relatively close to the disruptions that a mental health crisis had caused in their lives. The third category consists of people who already are 'living well in the presence or absence of mental illness', and have a clear focus in the recovery process. This finding is consistent with the different focus points in the stages of stabilisation, reorientation and reintegration mentioned before.

relations, to make a change point in another area, such as work (Strauss & Carpenter, 1977; Strauss *et al.*, 1985). The pattern of establishing a foothold in one area before attempting to make progress in another is relatively common. This is shown in the next example.

> A person stayed home with her parents and did very little socially or occupationally for 3 months following hospital discharge. After that period, she returned to work and increased her level of social and occupational function steadily over a 3-month period to a point well above the level she had lived at for several years before the onset of her psychiatric symptoms. (Cited in Strauss *et al*., 1985, p. 292)

2.8 Recovery factors

A cluster analysis of all the reviewed narrative studies reveals four clusters of personal factors and one cluster of environmental factors related to the process of recovery. These clusters can be regarded as dimensions of a recovery process.
The clusters are the following:
1. Factors that provide personal motivation to initiate recovery and to move forward
2. Factors belonging to the development of competency for coping with the illness and the environment
3. Factors contributing to the reconstruction of the identity
4. Factors of social engagement
5. Environmental factors that serve as resources for recovery

In Figure 2.2 below, these clusters and the major common factors evident in the analysis are depicted. Thereafter I discuss each dimension, describing the factors within each cluster and pointing out the relationship with other clusters or factors.

Cluster 1: Drives for recovery

For engaging in and persisting with a recovery process, a number of intrinsic motivational factors came to the fore during the analysis. The will to change or make progress is indispensable. Motivational factors are the empowering forces for recovery. These factors are closely related to the types of transitions discussed before.

A first factor is of a negative kind. Often, at 'rock bottom', a decision is made that life should not be continued, because the suffering has become unbearable and/or someone does not see any future perspective. What is *not wanted anymore* is turned into a strong appeal for help or a drastic change of strategy, often marked by turning a passive into an active mode. Negativity is turned into a force that intends to make a change.

Another factor is having the *desire and commitment to contain the illness and its consequences*. The person wants to cope better with the stress factors connected to his or her personal vulnerability in order to prevent relapse.

The factor *wanting to create meaning and to make positive life changes* is often associated with (re)developing identity (Cluster 2) and the desire for social participation (Cluster 4).

MULTIDIMENSIONAL MODEL OF RECOVERY

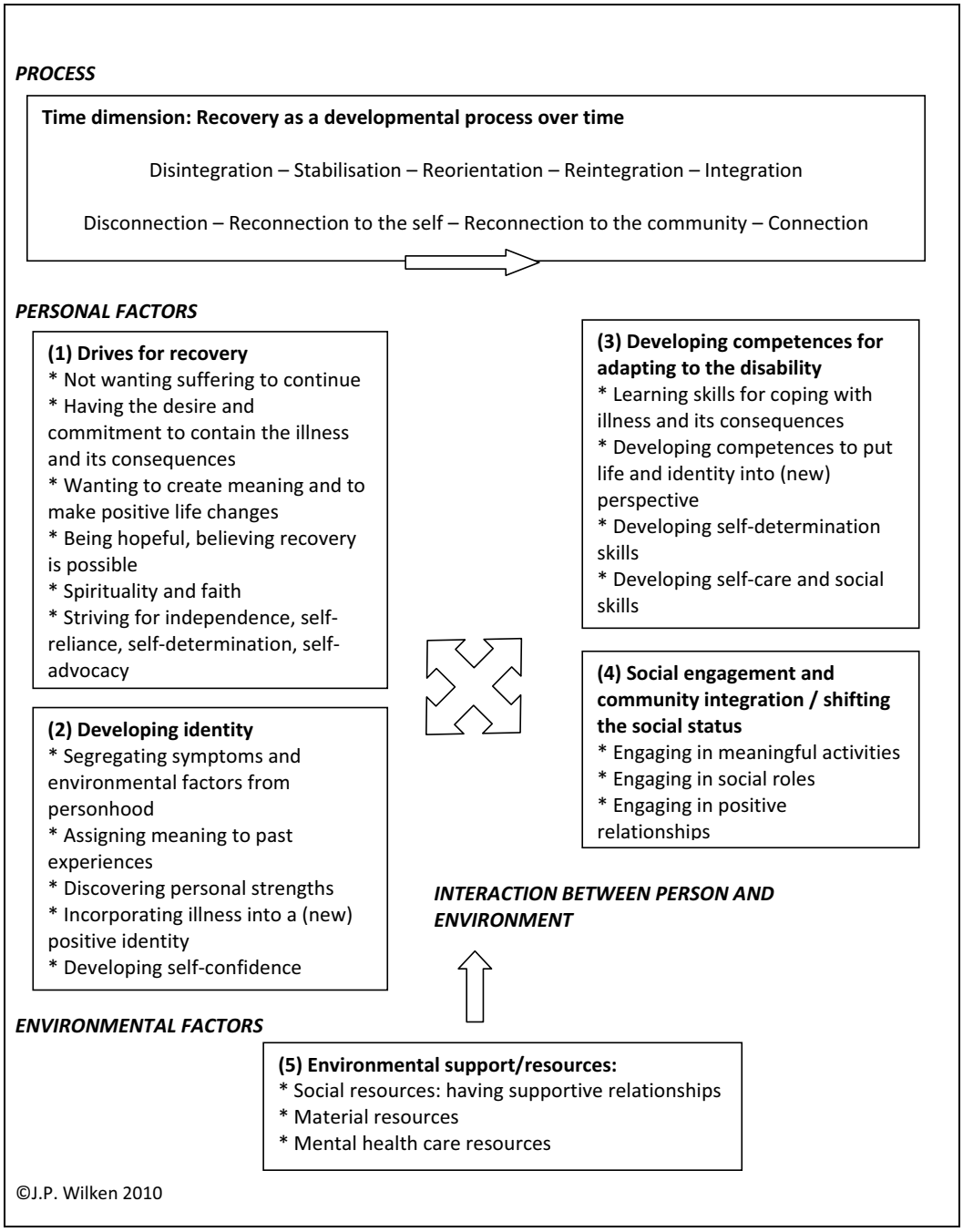


Figure 2.2: A multidimensional model of recovery

In many studies *hope* comes forward as a strong motivational factor. This hope can come from many different internal and external sources, for example spirituality and faith, or good examples of others with similar experiences. It is important to believe that recovery is possible and that this belief is supported by others (see Cluster 5). Spirituality and faith, besides providing hope, also provide support to hold on and to persevere despite difficult circumstances.

The last motivational factor entails the desire to become less dependent on others. This is the desire to become *more self-reliant* and to increase self-determination and self-advocacy.

Cluster 2: Developing identity

The second cluster contains factors that are related to the development of the personal identity. The studies show that illness and events cause a distortion in the conception of the self. A person has to (re)discover who he or she really is. Depending on the person's age and the situation before the onset of the illness, the identity to a greater or lesser extent has to be constructed or reconstructed. Young and Ensing (1999) in this regard refer to 'rebuilding a sense of self'.

Five factors came to the fore during the analysis. The first is that a person is learning to *segregate psychiatric symptoms and environmental factors from the personality*. Psychiatric symptomatology such as psychotic delusions can severely disturb the self-image. The person now realises that being psychotic is different from being *a* psychotic. The person is not the same as the disease. Examples of environmental factors are stigmatisation by a psychiatric diagnosis or the effects of long-term hospitalisation, by which the identity has been reduced to 'being a patient'.

A second element is that the person is *assigning meaning to past experiences*. To many people the past was a knout of events in which the self, the disease and occurring events were confusingly interwoven. The person for instance wants to sort out the order of events, and the causality between circumstances, a particular event, a disease and a disability. By gaining more understanding of what has happened, the role of the self becomes clearer. This process of life reviewing is often connected to mourning and trying to accept what has happened. In addition, vulnerability or a disability has to be accepted. It seems that the acceptance of a disability is easier when it can be placed in a past perspective that can be more or less understood.

A third element of developing identity is the *discovery of personal strengths*. These strengths are for example the strengths to overcome crisis situations, social skills, a personal virtue or the talent to write stories or poems.

A fourth element is *incorporating the illness/disability into the core identity*. This usually requires that a person has a clear picture of the vulnerability, and accepts what apparently cannot be changed. It is also the acknowledgement that the vulnerability is just a part of the self, and that other – strong – parts are also there. By re-establishing a positive identity, the sense of agency and autonomy is also strengthened.

A fifth element is *increasing self-confidence*. Self-confidence is boosted by developing more competences (Cluster 3) and engaging in activities where personal competences can be used and valued (Cluster 4).

Cluster 3: Developing competences

Competences are a combination of attitude, knowledge and skills, which enable a person to function in certain areas of life and enable him or her to have a desired degree of independence and autonomy.[9] In the process of recovery, not only the acknowledgement of existing strengths but also the development of (new) strengths is important.

An important factor is *learning to cope with the illness and its consequences*. This learning process is fuelled by the desire and commitment to contain the psychosis and its damage. The purpose is to develop a conscious and active stand towards the disease. This includes learning skills for coping with stress factors for which someone is sensitive. These stress factors might be intra-psychic, social or physical. People are eager to collect knowledge about their disease or disability. They get information from professionals, by reading books, by searching the internet and by asking peers. A number of people need to learn how to control thoughts, words and actions. Skills are acquired through self-experimentation, psycho-education, cognitive therapy, learning to use an early warning-sign plan and knowing how to benefit from counselling.

Taking care of the disability is closely related to *self-care skills*, although this is a broader area. Many people indicate that good self-care is essential. They mention that self-care includes getting proper sleep, maintaining a balance between rest and activity, eating well and keeping the house tidy. A specific self-care skill is medication management. For most people, medication is important to control the disease. Medication management includes knowing which medication and which dosage to take, at what time it should be taken, being disciplined to take the medication, self-monitoring when a condition is changing and medication should be adjusted, and having regular medical checks.

For people struggling with substance abuse, an important area of competence is learning how to control the substance use.

Another area of competence is *managing strengths and vulnerabilities* when (re)entering social life, such as education or work, in order to maintain stability. The illness can lead to activity and participation restrictions, and the challenge is to reduce these restrictions as much as possible. One important restriction that became evident from the studies is stigmatisation. The person has to learn to cope, both with self-stigmatisation (connected to Cluster 2) and with stigmatisation by the environment. As far as the latter is concerned, competences such as knowing when and what to tell about yourself and correcting wrong images are of concern. Dealing with wrong perceptions of other people requires social skills. Knowing when and how to express vulnerability and give details of a psychiatric past is part of this.

Social skills are also needed in a more general sense for developing and maintaining social relationships. In a number of studies it is indicated that social skills are impaired either by

[9] These notions will be discussed in more detail in the next chapters.

the disease itself or by hospitalisation. Social skills that have been acquired in the past are mostly intact, but the person needs sufficient self-confidence to start reusing them. In other cases, new social skills have to be learned.

Another area of competency is what I call *self-determination skills*. These are the skills that are needed to stand up for yourself, to give your opinion, to make decisions and to take responsibility for your life and behaviour. These are competences needed for autonomy and independence. Developing these skills often requires being able to express yourself. It also requires self-confidence and communicational skills.

Finally, a specific area of competence is formed by the competences that are needed to put life and identity in (a new) perspective. This is an area that is related to Cluster 2. It requires some cognitive ability to put things in a time perspective and to acquire insight. It also requires communicational skills in order to tell or write about the personal story.

Cluster 4: Social engagement and integration

Cluster 4 contains a number of factors that are associated with social relations and community (re)integration. In the process of recovery, at a certain point in time people take steps to change their social status. This active change is marked by engagement – the person is (re)connecting him- or herself. Three forms of engagement come to the fore from the studies: engaging in meaningful activities, engaging in social roles and engaging in positive relationships.

Engaging in *meaningful activities* means that a person takes up activities that are meaningful to him or her. This does not necessarily mean that these activities have a meaning for others. It may well concern 'in-house' activities, such as doing household work, reading literature or practising a hobby such as painting. Meaningful activities are also connected to *social roles*. People take up the role of a classmate (education), a colleague (work), a neighbour or a family member.

A third kind of social engagement that is emphasised in the studies is the engagement in *positive relationships*. People consciously choose to enter relationships that offer them pleasant and meaningful interactions. Topor (2001) mentions a number of functions that others can fulfil, such as

* serving as vicarious bearers of hope;
* providing material support;
* being recipients of meaningful behaviour;
* symbolising continuity and wholeness in the person's life; and
* providing a relationship that can be used to test the viability of the recovery.

Having a paid job is considered in many studies to be desirable, because it provides not only opportunities for socialising and developing new relationships, but also a meaningful social identity (Cluster 2) and opportunities to use and develop skills (Cluster 3). In addition, it provides financial independence, which contributes to autonomy (see also Curtis, 2000).

While engaging in social relationships, it is important not to lose balance (Boevink *et al*., 2002). Relationships may also cause stress. Here the disability-management competences

from Cluster 3 are important to maintain stability. At the same time, entering personal relationships provides the opportunity to experiment with coping strategies.

Activities appear to be important, not only because they help to structure and fill the person's time, but also because they provide opportunities for the person to explore and express aspects of him- or herself, give meaning and purpose to the person's life, offer enjoyment and pleasure, contribute to a positive and effective sense of self-worth and belonging and, finally, help to counteract symptoms (Davidson *et al*., 2005).

Specific environments in the community that are supportive for recovery seem to "foster an interplay between being with others who are supportive and/or receptive to support, and doing things that feel meaningful, ultimately kindling – and over time building – a favourable redefinition of self" (Sells *et al.*, 2006, p. 15).

Cluster 4 contains factors that contribute to interconnectedness with others. By (re)connecting to the community and becoming part of it, self-confidence and self-development are stimulated. People shift their status from a 'disabled' to an 'able' person, a person who is not only at the receiving end but also at the giving end. Self-confidence is achieved by socialising with other people and fulfilling a role in which they can make a contribution to a good cause (Tandy, 2003).

Cluster 5: Support through environmental resources

A fifth cluster of elements contributing to recovery entail environmental resources that offer support. These elements can be divided into personal and material resources. Resources should be supportive and provide opportunities.

Personal resources

All the studies mention the importance of others that offer support with different aspects of the recovery process. Recovery requires support and partnership. It is not accomplished alone. Supportive relationships are described in terms of people believing in me, people giving hope or people having positive expectations. Support can also take a practical form, such as help with finances, the household or finding a job.

Many different supportive others are mentioned, such as family members, friends, members of religious/spiritual and cultural communities; fellow-patients, clients, consumers, residents and professionals. It is clear that having others believing in one kindles optimism and hope. Remarks such as "People believed in me", "People had faith in me" and "People gave me hope" were ample. Tasimauri expresses herself as follows:

> "It was very positive to be around people who were so supportive of me and so concerned for my wellbeing and it gave me a lot more joy and a lot more spark for the future." (Tasimauri, cited in in Lapsley *et al*., 2002, p. 71)

It is important to have friends and family who are supportive, but who do not undermine the person's self-determination. A number of studies mention pets as valuable supportive others.

In a number of studies, the importance of peer support is mentioned. Involvement in the movement of users of psychiatry, peer-support initiatives, recovery groups or advocacy groups serves multiple purposes. This form of support provides affirmation of experiences and motivation (Cluster 1), contributes to developing the identity (Cluster 2) and competences (Cluster 3) and is a form of meaningful social engagement (Cluster 4). Furthermore, such peer groups can help to overcome stigma and find acceptance and a sense of belonging. The meaning of peer support groups is illustrated in the next example:

> "My peers and friends in support groups did understand, and they never tried to 'treat' me. Instead, they gave me love, understanding, kindness, and support. I built upon my experiences in the support groups and started to heal." (Pat, cited in Cohen, 2005, p. 349)

Material resources

Material resources needed for disease/disability management are medication and a safe and supportive place to be available in case of relapse.

Material resources needed for social participation include having a means of income, safe and decent housing, education, health care, transportation and a means of communication (e.g. a telephone). An own place to live appears to be an important factor for recovery (Borg, Sells, Topor, Mezzina, Marin and Davidson, 2005). This is shown in the next example of Carol:

> "I spend a lot of time on my own because I have an enormous need to unwind and chill out. To recharge my batteries . . . when I'm around people I get so worked up that I need time to calm down, so that when I spend time with people I like to retire early because I need several hours of peace and quiet on my own before I can go to bed." (Carol, cited in Davidson *et al*., 2005, p. 188)

Some European studies mention the social insurance system as a resource to maintain a basic living standard as long as the disability does not allow the person to acquire enough financial means through a paid job. Kari from Sweden is stating:

> "It was important that I got social benefits. It turned out that I was eligible for some pension points because I got ill before I was 24 years and there is a law ... I was receiving minimum pension. And that was a tremendous relief. Because when I lived at home and stopped smoking I managed to get by on minimum pension. But the thought of moving into my own place with only a minimum pension was tough. So the fact that I got some pension points and more money was a good step in the right direction. That was a burden lifted from my shoulders because then I knew that I could manage living on my own later and not having to worry about my financial situation." (Kari, cited in Mezzina *et al*., 2006a, p. 53)

Mental health care resources

For the sake of this study, mental health care resources are taken together as a separate cluster of factors. Mental health care resources can also be divided into personal and

material resources. This cluster entails the importance of finding the 'right services' and the 'right helpers' (Smith, 2000).

The presence and support of professionals is important – professionals who genuinely care, have positive expectations and an encouraging way of working, and allow enough room for people to follow their own way. This is illustrated in the example of Annica:

> "And they tell me: 'Don't give up, keep trying, you look nice and you're outgoing and you're creative and you'll surely find some job somewhere'. And, like, when I got a job at a large department store, just as an extra, they said: 'Congratulations!' and hugged me and congratulated me, saying: 'How well things are going for you'." (Annica, cited in Davidson *et al*., 2005, p. 191)

A number of studies list qualities of professionals that are considered valuable. On a relational level, these include an attitude of equality, unconditional acceptance, understanding and empathy, confidence, availability, openness, the ability to listen, genuinely caring, providing confirmation and ensuring a sense of belonging. Professionals should not be primarily interested in symptoms and problems, but in the person as a whole. Furthermore, aspects are mentioned such as having patience, giving emotional support, being trustful and respectful and instilling hope for recovery. A positive way of working is appreciated – a way of working that provides enough room for expression, self-direction and self-development. This is illustrated in the next quote:

> "It was just accepted as fact that that's how it was for you, they weren't trying to put words in your mouth ... you were listened to ... we were treated as people, not just self-harmers." For Pippa, being actively involved in treatment and having a sense of control was important, as this had never occurred before during her long history of contact with mental health services. She noted that although the programme might implement a safety contract if anyone was at risk, "you're the one who comes up with what's in it ... you're the one who decides what action to take ... and they'll just support you with it ... they'll suggest things, not force things on you". (Barnett & Lapsley, 2006, p. 60)

Being listened to and keeping the direction and responsibility in the hands of the person seem important elements of recovery-oriented care. Safety is important: services should "offer a place that is about getting people on a safe road to recovery" (Barnett & Lapsley, 2006, p. 62) – people such as mental health staff who inquire about and take into account their living circumstances, their histories and their aspirations, and who are concerned about their overall wellbeing. They want to be encouraged to maintain and expand their normal lives and social networks, and have useful support for career and education aspirations, as well as sensitivity to housing arrangements. They like to be seen as individuals, with their own values and cultures. Continuity is also important, so that people can develop relationships with staff and not have to tell their story over and over again to strangers.

Professionals are appreciated who validate people's experiences, respect them and treat them as intelligent people who have something to contribute. They should be professionals

who believe in the person, who focus on their strengths and believe in their potential to contribute and achieve (Borg & Kristiansen, 2004).

On a practical level, professionals are valued who recognise needs for assistance, make (extra) efforts on behalf of the person, give adequate and effective advice, and provide good-quality services such as psychotherapy.

Topor *et al.* (2006) mention a number of ways in which professionals can play an important role in the recovery process, namely (1) conveying information to the person because of their formal position as a professional and by virtue of this expert status; (2) serving as an intermediary for various interventions that involve money, activities, groups, housing, occasions for socialising, and so forth; (3) doing more than their formal role required; and (4) doing something different than what the person had come to expect. This is illustrated by the next example:

> "After I had worked there for a month she came and gave me a rose. It's dried up now and I have it at home. Small things like that." (Vera, cited in Topor *et al.*, 2006, p. 31)

As far as material mental health care resources are concerned, services should be responsive. This means that services should adequately and flexibly respond to the needs of the person. In case hospitalisation is needed, this should be in a safe and friendly and the least restrictive environment. Services have to contribute to increasing strengths and competence in coping with vulnerability and life stress and to explanations of what has happened or how the disability is constructed, and have to lead to the exploration of issues of identity and new possibilities for increasing autonomy. In the stabilisation and reorientation phase, individual psychotherapy is generally mentioned as the most appreciated form of professional assistance, although studies among young people indicate that for them, group psychotherapy and other group activities in which sharing with peers is important are regarded as valuable. In a number of studies, specific forms of therapy are mentioned, such as cognitive behavioural therapy, psycho-education and training programmes focused on illness management (e.g. Mueser et al, 2002).

In most studies, medication is mentioned as an indispensable resource. Often, a struggle is mentioned to find the right type and dosage of medication. Here, a close collaboration with a psychiatrist is mentioned as being important. People appreciate a psychiatrist who works with them on an equal level, takes the opinion and experiences of the person seriously, and takes care to prescribe medication that gives the best results with the minimum of undesired side effects.

2.9 Interaction between recovery factors

I hypothesise that within clusters, and in the interaction between factors in different clusters, changes occur that may lead to progress or decline. Here the phenomenon of *transition* is important. In recovery and rehabilitation, the *sensitivity for change* may well be one of the most important conditions (and a field of study about which there is still much to discover).

Change may occur in all of the clusters. It can happen within one cluster, and influence the factors in one of the other clusters. It can also happen simultaneously as a result of events in other clusters. It seems that in the course of time, a transition is made when a number of factors from different clusters are strong enough, for example, if the will to be more self-reliant is strong enough (Cluster 1), there is enough self-confidence (Cluster 2), the person has sufficient competences (Cluster 3) or longs to develop them (more) in a new social context (combination of clusters 1 and 4). An actual transition in Cluster 4 is often made when opportunities come along (Cluster 5) and the person is ready to take them.

A term used in the literature in both recovery studies and rehabilitation is *readiness* (e.g. Anthony, Cohen, Farkas & Gagne, 2002). The individual must be ready to make a move. From the review it becomes clear that many different motivational factors (cluster 1) may constitute this readiness. These factors include hope, creating meaning, believing that recovery is possible, spirituality, willpower and different forms of empowerment. These motivational factors may be mediated by external stimuli (Cluster 5).[10]

Recovery as a socially mediated process

The reconnection to the self is closely connected to reconnection to the community. A number of authors describe recovery as a social or socially mediated process (e.g. Borg & Davidson, 2008). The reconstruction of the identity takes place in a 'negotiation' with external circumstances, as Ochocka *et al*. (2005) call it. It is a dialectic process in which each individual continually tries to make sense of and respond to the dual realities of what is going on inside him- or herself and the external circumstances within which he or she lives. I may add to this that there is also a historical dimension in this process (Judge *et al*., 2008; Lapsley *et al*., 2002; my study in Chapter 3). People also have to 'negotiate' with what happened to them in the past. This seems to be important in order to make way for new developments.

The recovery process is motivated by a drive to 'move forward'. Cluster 1 identifies a number of factors that provide strengths to go on in a desired direction. In the stabilisation phase of the process this direction may still be vague, and none other than fuelled by the desire to get rid of the oppressive character of the situation, which causes much suffering. In

[10] These factors do not seem to differ from people with (other) chronic illnesses. Feldman (1974) reports that people feel that they are victims of impersonal forces operating upon them beyond their comprehension and control. Improved functioning, Feldman argues, requires a redefinition of the problem that diminishes the sense of being a victim and that increases the sense of control. He calls this a transition from an identity of being 'sick' to one of being 'different'. This transition usually involves a period of denial and mourning before the past can be relinquished and the future considered. Feldman writes: "To discover a new meaning in the face of dissolution of the old meaning, to accept the differences imposed by the illness, and to still maintain one's dignity and worth is the essence of the transition from sick to different. When one has accomplished this, there is no need for illness as a primary life style" (Feldman, 1974, p. 289).

the reorientation phase, the desired future perspective becomes more articulated, and may obtain shape in the form of concrete goals. External support, as identified in Cluster 5, is an important contributor to the motivation for recovery. All studies mark the encouraging and ongoing support of other people as indispensable.

Three areas of recovery

It seems that a combination of strategies leads to positive change. These strategies seem to be aimed at the following three important areas:
- The area of the illness and the disability (mainly factors in Cluster 3)
- The area of the personal identity (mainly factors in Cluster 2)
- The area of social functioning (mainly factors in clusters 3 and 4)

Coping with vulnerability

In the first area, we see that people use and develop strategies to cope with the illness and the disability. They find ways of dealing with stress and vulnerability.

In the second area, people (re)discover and reconstruct their identity. In this area, people look at the meaning of experiences and try to figure out which aspects of the self are 'original' and which factors are associated with the illness and/or with external circumstances.

The third area concerns the relationship between the person and the world. This is the domain of functioning as a human being, both in terms of self-care and in terms of interpersonal relationships.

In the process of recovery, the emphasis seems to be first on the area of the illness and the disability, then shift to the area of the personal identity and subsequently to the area of social functioning. There is close interaction between factors within these three areas. Identity formation is strongly influenced by the illness, the disability and its personal and social consequences. Reconstruction is influenced by the discovery of personal strengths and interaction with others.

Identity development

From the angle of identity, the development of the personal identity can be seen as the transformation of an illness and disability identity to a social identity. This is illustrated by the next figure. In chapter 5 I will connect social identity to the notion of citizenship.

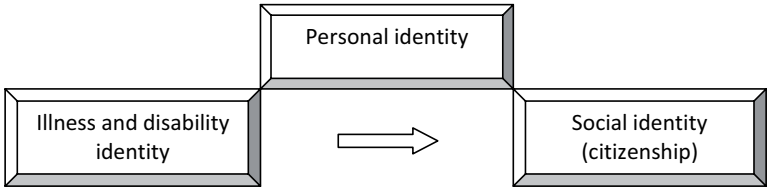


Figure 2.3: The development and transformation of the personal identity

First, the person has to sort out the core of his or her psychological 'self' as separated from psychiatric phenomena or the identity of a 'psychiatric patient'. Second, the person has

to sort out his or her identity in relationship to the world. This part concerns existential values and desires and preferences with regard to personal relationships. The shift towards a social identity is made when the person actually engages in social activities and becomes involved in social roles (Cluster 4). The social identity is not an illness or disability identity any more, but an identity of a fellow human being. From a community perspective, this is a move towards a citizenship identity, when someone is part of society and fulfils different roles.

Interacting with the environment

A person constantly has to interact with physical and social environmental factors. These factors may either be positive, negative or neutral with regard to the recovery process. Negative factors that came to the fore from the studies are lack of support, stigma, unresponsive or inaccessible services, poor-quality housing, unemployment and poverty. Positive factors include social support, responsive services, appropriate housing, work and financial means.

It is interesting to look at the ways in which people deal with both negative and positive factors. Ochocka *et al*. (2005) identified two types of strategies, namely accommodation-oriented negotiations, which involve the acceptance of or the adaptation to the situation, and action-oriented negotiations, which involve change-oriented thinking and action. Competences mentioned in Cluster 3 are needed to be able to use these strategies and to make successful connections to the social environment (Cluster 4). From some studies it becomes clear that negative factors do not always have to be negative per se. In a number of studies, the notion of *resilience* appears to be important. People discover their internal strengths by resisting negative circumstances. By taking an active stand, for instance by protesting and resisting, a transition is made, which can often in retrospect be marked as a point at which recovery started.

The factors in Cluster 5 constitute the external support framework for the individual recovery process. If a good match can be made between environmental resources and the individual factors in clusters 1 to 4, advances in recovery can be made. External resources contribute to motivation and empowerment, to the development of identity and competences and to engagement and social integration.

2.10 Summary and conclusion

Recovery seems to be an interactive process of psychological, biological and environmental factors. Studies do not show significant differences in recovery processes on the basis of ethnicity, gender and diagnosis. Ochocka *et al*. (2005) point to the spiral character of the process in which positive transitions are the product of successful negotiation between internal conditions and external circumstances. The outcome of this interaction can also produce setbacks, but the authors anticipate that if the drive to move forward is strong enough, these setbacks will not interfere with the overall process. How this interaction works exactly and when it leads to progress or deterioration, is still not clear. One important aspect seems to be that people's attributions or casual explanations of what has happened to them, including those pertaining to the degree of control (controllable versus uncontrollable), locus of control (internal versus external) and degree of stability (stable versus unstable), strongly influence people's attitudes and behaviours. Another important aspect is the interaction between person and environment.

A recovery process is characterised by development, growth and empowerment. In the first phase the emphasis is on disease management. After some basic stability has been reached, people enter a phase of reorientation. Reorientation is focused on two aspects: the disability, the self or the identity; and the self and the community. People assess the nature and consequences of the disability. They start reconstructing their *identity*, looking back at what has happened to them, trying to make sense of events, and bereaving what has been lost. In this reconstruction process they segregate the illness from the healthy sides of personhood, and at the same time integrate disability into the core identity. Mancini (2003) states that the heart of this process is the transformation from an illness-dominated identity to one marked by meaning and wellbeing.

Step by step, and sometimes with an interlude of standstill or setback, people become more self-assured, more knowledgeable and more skilled. This could be summarised under the notion of *autonomy*. While in the second phase people work on psychological integration, in the third phase, they move towards social integration. Concrete steps are set in one or more domains of life, such as independent living, going to school or having a job. People strive for independence, become more and more socially integrated and experience increased wellbeing.

The transitions between different stages are caused by different factors. In the worst of despair there is an almost instinctive reaction for survival. A next common factor is an insight into or awareness of the current situation, which provides motivation to work on further assessment and find or accept help. A transition can also be made when people are able to express their emotions and thoughts and are able to articulate hopes and dreams. The development of a sense of agency, a (first) form of empowerment, gives fuel to further growth, the reconstruction of identity and the development of more autonomy. A final transition is marked by an active connection that is made with the environment or community, by making a change in one of the domains of living, work, education or relationships.

This study reveals the contours of a meta-grounded theory on recovery. Although it is known how recovery processes develop in general, and which factors are important in this

process, there is still a lot of research to be done on the different clusters and their mutual interaction. It is known that premorbid factors such as positive personality traits and a life history with positive experiences (social relations, job experience) are positively correlated with recovery outcomes. However, from the experiential studies it appears that recovery is also possible for people who lack those experiences (for example because they lived in very deprived circumstances or were still young when they got ill). More must still be learned about the exact influences of impeding factors and the ways people can overcome them.

The relationship between intrinsic and extrinsic factors and the relationships between motivation, competences and social participation require more research. It is still unclear how different elements in a recovery process come together over the course of time. It is assumed that for every individual the composition is different. It is like a jigsaw puzzle: One has to look for pieces that fit together and are meaningful at this stage of the process. These can be either consolidating factors, push factors or pull factors. If the different elements *synchronise*, for example meeting the right support person at the right time when you are susceptible to make a change in your life, then development takes place. By putting pieces together bit by bit, a complete composition slowly comes into sight.

In the process of recovery, the notion of *empowerment* seems to form a golden thread. It can be connected to all the clusters. The process can be characterised by continuous and growing empowerment. Empowerment is a central feature of motivation. By acquiring competences, empowerment is enhanced. As a result of the empowerment of the self, transitions can be made towards meaningful activities and social roles. The support of material and personal resources empowers the person and thereby contributes to his or her recovery process. In chapter 5 I will put the notion of empowerment in a broader context.

People gain control over their lives through access to meaningful choices and the resources to implement those choices. The findings document the crucial role that information and choice play. Having information on and access to a range of meaningful and useful choices and options foster recovery. Participants are empowered when they make choices regarding where to live, finances, employment, personal living / daily routine, disclosure, who they associate with, self-management and treatment. People talk about the empowering experience of choosing “how I see myself, my disorder, my situation, my quality of life”. But for such empowerment to occur, meaningful options must exist and people must have training and support in making choices, and the freedom to take risks and fail. Too often, quality-of-life choices seem outside the realistic reach of many people. Options are limited, lousy or nonexistent. Participants recounted service providers, professionals and family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination and stigmatisation.

Independence (defined as not being subject to the control of others) also falls within the empowerment dimension. In the study of Onken *et al*. (2002) participants expressed it as both a process and goal of recovery. Independence is achieved through making one’s own choices and decisions, exercising self-determination, enjoying basic civil and human rights and freedom, and having a liveable income, affordable housing, and so forth.

What undermines independence are paternalistic responses, lack of respect, involuntary and long-term hospitalisation, stereotyping, labelling, discrimination and the risk of losing what benefits and support one does have. Repeated encounters with such experiences instil fear, a lack of confidence and negative attitudes and beliefs. Some participants in the study of Onken *et al.* (2002) talked of the importance of both independence and interdependence, reaching beyond the goal of independence to that of embracing interdependence. Interdependence is a term that implies an interconnection or an interrelationship between two entities and is used to describe the link of people to people. Seeking independence and seeking interdependence are not mutually exclusive. Limitations in funding, geographical availability, participation and leadership-development opportunities, as well as a lack of transportation and controlling and mistrustful professionals hinder peer-support efforts.

The formal health service system, and the professionals and staff employed within it, constitutes another impact on recovery. Progress towards recovery can be supported through the formal system. There was, however, much more 'hindering' content in the data regarding formal systems than any other domain. The mental health system often hinders recovery through bureaucratic programme guidelines, limited access to services and support, abusive practices, poor quality services, negative messages, lack of 'best practice' programme elements, and a narrow focus on a bio-psychiatric orientation that can actually serve to discount the person's humanity and ignore other practical, psychological, social and spiritual human needs.

Recovery can be regarded as a spiral *development process*. The (clusters of) factors mutually influence and reinforce each other. For example, developing social skills (competence) boosts the self-confidence (motivation). By getting positive feedback (social support) while engaging in a social role (shifting social status), empowerment of the self is increased (motivation), and provides courage to undertake new actions/interactions.

In the recovery process, from disintegration to integration, and from disconnection to connection, different sets of contexts, intervening conditions and actions/reactions will be attached to the different stages. Since recovery is not a linear process, the challenge will be again and again to use the model as a tool to assess where the person is now, and as an aid that may point out certain conditions, actions and interventions that may be useful in this individual's recovery process.

Recovery is a process that takes place in a strictly individual timeframe. How fast or how slow this process goes, is fairly unpredictable. From the longitudinal studies it is clear that there is great variance in the length of the recovery process. From more recent studies on recovery from first psychosis (e.g. Barnett & Lapsley, 2006; McGorry *et al.,* 2008), the hopeful message is that early interventions, such as the organisation of adequate support from the social network and the provision of good medication, education, counselling and supportive out-patient mental health care services, may significantly reduce the time needed for symptomatic recovery, and thereby possibly also favourably influence social recovery. However, more research is needed to collect more knowledge of the relationship between the length of a recovery process and facilitating factors.

Again it is important to emphasise that recovery is a personal process that requires the time as is needed by the person. From the studies it becomes clear that too much external time pressure may harm the process. Environmental support should be finely tuned to the stage of the process and the needs connected to what is important for the person in this particular stage, looking at which (cluster of) factors could be strengthened.

In most of the qualitative studies the focus was on the personal process and the individual factors that contribute to recovery. There might be a cultural bias here, because most studies were conducted in Western countries, with a strong emphasis on the potential of individuals to grow. Additionally, especially in the USA, narratives are influenced by the 'discourse of recovery', as positioned by the figureheads of the recovery movement. However, the study of Davidson *et al.* (2005) in four different countries, and the studies of Lapsley *et al*. (2002) among a Maori population in New Zealand and of Song and Shih (2009) in Taiwan, show that there are no significant social or cultural differences in the processes of recovery. Cultural differences between participants from each country were noted primarily in the nature of the opportunities and support offered rather than in the nature of the processes described.

In addition to the individual factors, numerous *environmental resources* are also mentioned, both personal and material by nature, which have as common characteristic that they function as personal support to the person. One of the types of support is the support offered by mental health services and professionals. However, most studies provide little specific information on this. Questions emerge such as: When is professional help considered to be supportive? What is meant by 'personal support', if it is described in terms of 'an attitude of equality, partnership, unconditional acceptance, understanding and empathy, hope and confidence' (Barnett & Lapsley, 2006)? What is meant by on-going, consistent, support (Smith, 2000), and why is this useful?

In order to increase the understanding of what effective *professional support* is, and how professional help becomes effective, I conducted a qualitative study by collecting, transcribing and analysing 13 stories of people with severe mental illness. The results are described in chapters 3 and 4. For the cause of this study I hypothesise that effective professional assistance, as one of the forms of environmental support, will contribute to factors in all the clusters of the model described in figure 2.2. Good professional care will support the person in his or her recovery process, if it is adapted to the needs connected to a specific phase of recovery. I thereby formulate the following hypotheses for the study described in the next chapters:

- Good professional care will contribute to motivation and empowerment (Cluster 1)
- Good professional care will contribute to the development of the identity (Cluster 2)
- Good professional care will contribute to the development of competences (Cluster 3)
- Good professional care will help the person to engage in meaningful activities and social roles (Cluster 4)
- Good professional care will help to improve the environmental resources needed by the person (Cluster 5).

Chapter 3 Dimensions of vulnerability and recovery

In this, and the next chapter, the results of a qualitative study entailing the analysis of 13 narratives of people with a history of severe mental problems are described. The aim of the study was to analyse their life stories and to examine what happened in terms of the origins of the disorder or (consequent) disability, the impact of the vulnerability, the ways in which the person dealt with the vulnerability, as well as the role of the environment. Special attention was given to factors that hindered or facilitated progress. Within this analysis there was a special interest in mental health care, looking at the services which the participants perceived to be helpful and what they considered to be good care.

> Reading tip: The findings of this study are presented in a condensed way. The findings are further explained in separate sections and illustrated through examples and citations from the narratives. These sections can be recognised by a smaller font and a two-column layout. The reader who is interested only in the main findings can simply skip these parts.
> One-column boxes are sometimes used to elaborate on a finding, or to explain a notion, for example by referring to relevant scientific sources.

3.1 Introduction

Many of the phenomena and factors reported in the previous chapter came to the fore during the analysis of the narratives. The findings of this qualitative study confirm the findings of the meta-analysis in Chapter 2. This indicates a certain degree of generalisability, thereby contributing to an emerging grounded theory of recovery.

In addition, in the qualitative study reported on in this chapter recovery appears as a developmental and self-empowering process over time, a process that consists of many different interacting variables. The complexity of this interaction makes every story unique. I was able to confirm the clusters identified in Chapter 2 on the basis of the data of these narratives. This study provides additional insights, however, thereby enlarging and refining the body of knowledge on recovery.

The chapter starts with an explanation of the research methodology (paragraph 3.2). Thereafter, a description of the characteristics of the group of participants follows (paragraph 3.3). In paragraph 3.4, I summarise the main findings of this study. Since these findings support many of the factors that came to the fore from the review in Chapter 2, I focus in the remaining part of this chapter on additional insights and new notions.

Additional insights in the process of recovery and the notion of *transitions* are described in paragraph 3.5. In paragraph 3.6, the notion of the *personal niche* is introduced. This notion was developed on the basis of the finding that most participants in the study had created a set of conditions in order to take care of their vulnerability. Different aspects of the work that people are doing on the *reconstruction of identity* are explained in paragraph 3.7. In paragraph 3.8, I pay attention to the ways in which people move towards social reintegration.

Paragraphs 3.9 to 3.12 are dedicated to the role of *environmental resources*. In paragraph 3.9, the notion of *social niche* is introduced. This concept is developed on the basis of the finding that most participants in the study used special environments that met the criteria of their personal niche and simultaneously enabled them to advance on the road of personal and social recovery. Factors associated with *social support* are described in paragraph 3.10. In paragraph 3.11, I present resources that emerged from the study that contribute to empowerment, a central concept in recovery. Finally, in paragraph 3.12, I investigate the contributions made by professional caregivers to support recovery, and the characteristics of professionals that were attributed to them by the participants.

In Chapter 4, I elaborate on these qualities of professionals, taking into account the results of a conceptual analysis to constitute elements of good care.

3.2 Methodology

Selection of participants

The participants in this study volunteered to be interviewed. They had heard about the project from professional workers or other participants or have seen announcements in local magazines of mental health agencies. Participants were selected on the basis of criteria for severe mental illness. Severe mental illness is defined as such on the basis of diagnosis, disability and duration, and includes disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic-depressive disorder and autism, as well as severe forms of other disorders such as major depression, panic disorder and obsessive compulsive disorder (National Advisory Mental Health Council, 1993). Major mental illness is related to severe disability, and a duration of illness of at least one year or intermittent periods of serious mental illness over a long period of time. Seventeen people wanted to participate in the study, of which two did not meet all the criteria and another two could not be interviewed due to various reasons.

Sample adequacy

The sample presented a good variation in terms of age, marital status, length of illness, social network, use of mental health services and phase of the recovery process. The majority of the participants were men. People actually living in a mental health facility were in the minority.

When comparing the characteristics with the characteristics of the participants in the studies described in the previous chapter, despite the small sample there seems to be sufficient exemplary generalisability (Smaling, 2009).

After having analysed the data of the 13 participants, I checked whether the sample met the criteria of what Smaling (2009, p. 6) calls “variation-covering generalisability”. If one considers both the characteristics of the sample and the primary analysis of the data, these confirm most of the findings of the literature on elements of the recovery process discussed in the previous chapter. This confirms that the sample is representative of the population of people in recovery of serious mental illness, in the sense of variation-covering representativeness as a basis for external validity and generalisability. A second check was whether the data set was ‘rich’ enough, i.e. that it provided enough variation in data to

permit valid analysis. This seemed to be the case, which is why I did not conduct additional interviews with the present group of participants or with new participants.

Procedure

Participants were informed both personally and by letter of the purpose of the study and the way in which the interviews would be conducted. I introduced myself, my background and my interest. The interviews took place during the year 2006. They were conducted at a place and time preferred by the participant. Interviews were conducted using the biographic-narrative method of Wengraf and Chamberlayne (Wengraf, 2001; Wengraf & Chamberlayne, 2006). This method entails simply asking the person to tell his or her life story, leaving it to the person to decide where to start. Questions during the interview are asked with the purpose of either obtaining more detailed information about a topic or event, or obtaining 'the whole picture'. These questions included, for instance, questions that clarify the chronological order of the story or questions asked to fill in gaps in the time perspective.

Each interview was recorded and transcribed. The transcriptions were sent to the participants. They were asked to send comments or information they would like to add. Also, the possibility was left open to conduct another interview. Some participants returned remarks, which were added to the transcriptions. The transcriptions were text analysed using the software programs Concordance and Examine32. Consequently, the transcriptions were analysed using a close-reading protocol developed by Schilling (2003) on the basis of the discourse-analysis methodology as described by Fairclough (1995; 2003). A cross-comparative analysis was done using a grounded theory approach (Charmaz, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990), as described in the previous chapter. The grounded theory approach is an inductive method suited for providing a detailed and comprehensive description of complex and subjective phenomena. First, on the basis of the close-reading analysis and memos, emerging themes were constructed for each narrative. Besides an 'open' analysis, a specific analysis was done searching for factors that could be part of a 'recovery discourse'. What did the story before, during and after the occurrence of a mental problem entail? Which factors hindered or facilitated progress? In this chapter, I describe the results of the search for individual and environmental factors. The chapter ends with an answer to the questions: What was the role of professionals and mental health services? What did the people perceive to be helpful? What do they consider as good care? The latter two questions were the only questions that were specifically asked in the last part of the interview.

The participants in the study were highly motivated to share their story. Although not all the participants had equal abilities to express themselves, it was possible to collect the 'full story' from each of them. Participants were very open and honest. Even when in the beginning there was some reluctance due to the fact that they did not know the researcher, they had enough confidence as the interview progressed to reveal personal details. The information given was adequate and reliable.

In order to achieve a degree of validity, results of the analysis were discussed with three of the participants in the study and critically examined by professor Andries Baart. On the

basis of their feedback, the analysis could be refined and concepts could be developed (i.e. a process of dialogical validation was used).

3.3 Participants

The group consisted of nine men and four women between the ages of 29 and 56 years. Most of them suffered from psychotic disorders with a length of illness of more than 10 years. Ten out of thirteen had been hospitalised in the past; most of them more than once. All of them have used different mental health services, and most of them are still using them. At the time of the interviews, nine participants were living in their own home, while four lived in a residential facility of the mental health or social system. Two participants had a paid job, while eight performed unpaid activities, mostly in a mental health programme. One participant followed an educational programme. Two persons were engaged in artistic activities.

Although the size of their social networks varied across the sample, more than half of the participants had a network of no more than 10 core members. In terms of recovery, there was great variation. At the time of the interviews, nearly half of the participants were still concerned about remaining stable, but were also in search of new possibilities for their life. More than half were in a reintegration process, or had been reintegrated into different social roles.

Table 3.1 shows in which phase the participants were at the time of the interviews. All participants were more or less stable at the time of the interviews, although their stories show that this is often a fragile kind of stability. Approximately one-third were in the process of orientation and exploring new perspectives. Approximately one-third were busy implementing steps to change their situation in terms of their home environment, work or education. The remaining third were satisfied with their life situation at the time. They were satisfied because they had maintained a balance over a longer period of time, and were engaged in valued activities and social roles.

Table 3.1 Participants' phase of recovery process

Participants' phase of recovery process	n
From crisis to stabilisation	-
From stabilisation to reorientation	5
From reorientation to reintegration	1
Reintegration	1
Partly reintegration, partly stabilisation after reintegration	3
Stabilisation at an integrated level	3

In Table 3.2, the characteristics of the participants are listed.

Table 3.2: Characteristics of the participants

Gender		*Age*	
Male	9	20–29	1
Female	4	30–39	7
		40–49	1
		50–59	4

Civil status		*Present living situation*	
Single	8	Own house	9
Married	3	Sheltered living	2
Divorced	2	Homeless shelter or group home	2

Actual occupation		*Social network*	
Volunteer work within mental health system	8	Size: > 10 core members	7
Paid job	2	Size: < 10 core members	6
Education	1	Social relations mainly within mental health system	6
Others	2	Social relations mainly outside mental health system	3
		Social relations both inside and outside mental health system	4

Professional services (used in present and past)			
Clinical treatment at psychiatric hospital	10	Outreach community mental health service	3
Outpatient psychiatric clinic	7	Residential mental health service	2
Alternative help	7	Somatic treatment at general hospital	2
Day care centre (mental health service)	6	Homeless service	2
Clinical treatment at psychiatric ward of general hospital	2	Addiction clinic	1

Diagnosis		*Length of illness*	
Psychotic disorder	7	< 2 years	-
Bipolar disorder with psychotic characteristics	3	2–5 years	2
Affective disorder with psychotic characteristics	2	6–10 years	2
Addiction disorder	1	11–15 years	4
		16–20 years	4
		> 20 years	1

3.4 Summary of findings

For most of the participants in this study, recovery was an ambivalent notion. Many of them did not speak about recovery as such, but used different terminology. I use the term recovery, in line with the international literature, but emphasise that the participants in this study had many different connotations to recovery.

The process of recovery was connoted as
- a process of *struggle* and *survival*;
- a process of reaching *stabilisation*, of finding a certain rest and balance;
- a process of *discovery*; and
- a process of *recreation* and *reintegration*, both internally in terms of reconstruction of the identity, and externally in terms of becoming part of the social world again.

It is clear that recovery is not a linear process, but that it is characterised by instability, moving back and forwards, with ups and downs. In its temporality, recovery is generally long term in nature, although there is much variety. In my study, some participants seemed to had moved to a phase of reintegration within one or two years, others indicated that this had taken them 10 years or more. The same variety was demonstrated in terms of pace. Sometimes changes occurred rapidly; at other times it took several years.

Apparently there are two sub-processes that constitute recovery. One is the process of *personal recovery*, which I call 'recovery of the self', or the process of personal (re)integration. This sub-process consists of two main tasks: (1) gaining control and taking care of vulnerability; and (2) developing identity. This leads to (more) self-control, and to a stronger or more integrated identity. The other sub-process is the process of *social recovery* or the process of social (re)integration. The task here is to work on social integration: becoming part of society. The outcomes of the first sub-process are awareness of personal assets (experiences, knowledge, skills, talents, aspirations) and competences to take care of personal vulnerability. The outcomes of the second sub-process are participation, valued social roles and meaningful activities.

The phases and transitions in the recovery process, as described in paragraph 2.7, can also be recognised in the narratives in this study. The process of recovery is a constant process of *interaction*. Interaction has two elements: interaction with the self and interaction with the social environment. My analysis supports the findings of Ochocka *et al*. (2005), who consider a successful 'negotiation' between these two types of interactions as critical for recovery.

The interaction with the self can be characterised as a self-dialogue, in which finding a meaning for what has happened (the crisis, the disease, the trauma) and coming to terms with these facts are central themes. All the narratives in this study show this. The process of constructing or reconstructing the narrative seems to be crucial for development. I discuss this in paragraph 3.7, using insights from the literature on reminiscence and the life review.

Part of the narrative is to understand the *vulnerability* itself. Understanding what it is and how it works makes it easier to find a way to handle different consequences of the vulnerability. From my analysis the notion of *the personal task* emerges. The personal task

can be defined as the daily struggle the person has with his or her own impairments; the attempt to keep a balance in order not to 'go under' or to 'go out of the mind'. It is a task someone has to perform him- or herself, but external support is often needed, for example in the form of medication or a 'watcher' – someone who helps the person keep an eye on him- or herself.

I here introduce the notion of *personal niche*, which emerged from the data. In order to be able to handle their personal tasks, these people have to know what their personal niche and its boundaries are. Discovering and determining the personal niche and gaining insight into how things work inside themselves are necessary to develop and apply efficient coping strategies. Handling the vulnerability is an important form of individual development. It means that the possibilities to participate in meaningful social activities and roles are increasing. From the narratives it appears that once someone is able to handle his or her personal niche, this provides a foundation for shifting the social status.

The other element of interaction is interaction with the social environment. Social resources are needed for many different purposes. They serve as support in the processes mentioned before: the process of coping with crisis, surviving, identifying and managing the vulnerability; the process of finding rest and stability; the process of discovery and creating a personal narrative; and the process of recreation of the identity and reintegration into meaningful activities and social roles. In this regard, other people act as support pillars. In the narratives, many different kinds of supporting people are mentioned, such as family members, peers and mental health professionals.

For the sake of recovery, many people use environments that provide safety, social contact, support and recognition. These may be environments in the domain of living, working or socialising. I use the concept of *social niche* to characterise these types of milieus.

The narratives in this study reveal a number of external elements that are valuable resources. These elements can be divided into personal and material resources. In the domain of mental health care, valuable resources are, among other things, medication to which the person responds well, safe environments and professionals who engage in a personal relationship.

3.5 Process and transitions

Time

In this study, the duration of phases in individual recovery processes varied to a large extent. During the process, there may be variations in the pace at which changes take place. In some stories, recovery took place quickly (this is especially the case with younger people); in other stories, change occurred at a slow rate. At times, periods of fast development were alternated with periods of consolidation. Time is needed to sort out issues from the past, to reflect and create awareness, to experiment with new behaviour and to develop strengths and confidence. Especially in periods during which the emphasis is on stabilisation, the time perspective is a short-term perspective, narrowed down to trying to manage oneself on a day-to-day basis. If transitions are made by forms of reorientation and development of future goals, the time perspective expands towards a more long-term perspective.

Time needed for recovery

In some of the cases in my study, from the outside it seemed as if nothing much was happening. Strauss (1989c) uses the term "moratorium" to describe a period during which little or no measurable behavioural or symptom change is noted. "It seems as if a person stops for a while to take a rest, to get new energy, to reconstitute his identity, or to strengthen his skills in subtle ways, which can hardly be noticed on a surface level" (Strauss, 1989, p. 23).

HM, for example, spent more than five years in hospital, apparently without showing any change. When telling his story, he simply stated that he had lost hope and given up. So, he had turned more or less into a 'passive mode'. From my study it seems that two major factors cause people to go into a certain 'frozen' position: a state of despair, or in other words a lack of hope, and a great degree of anxiety. A number of participants stated that they were so afraid that they just could not move. A transition starts when 'unfreezing' begins.

> *So those months really sucked. I really suffocated from fear. I barely dared facing my friends. So, somewhere in the summer, I felt quiet again; everything was more or less under control. Then I took up my work again.* (AD)

It takes time to become aware of how things work. In most of the narratives I detected forms of life reviewing (Bohlmeijer, 2007a) or rehistorisation (Petry & Nuy, 1997). The participants were busy (re)constructing their biography. They needed sufficient time to do 'narrative work'.

> *And very slowly, I began to understand how it works in me.* (EH)

> *It is just time, that's maybe factor number one […] Time, rest, no pressure on the kettle, that is the most important.* (PV)

> *It is never contained, but probably I already had it when I was at the age of 13 or 14. I was always very good at sports, but I was also always afraid to fail.* (AD)

The journey of recovery requires a huge amount of patience.

> *And then, very slowly, I likes doing some things now and again.* (HM)

> *My first psychosis was in 1989, we are now in 2006. Now you can see, every time there was a dip. But every time, you made progress, millimetres is even too much to put it, but each time you advanced a little.* (EH)

> *The process of acceptance takes 13 years. After 13 years you start to slowly accept that you may be there, that you have your disabilities, and that you accept, yes, that I live from social benefits.* (RL)

At times, the participants experienced a kind of flow, a period in which the transition took place at a rapid pace. A number of positive elements seemed to come together, for example good response to medication or therapy, the support of friends or a new pet in the house.

This is exactly happened with PV, who stated as follows:

> *The last months I have the feeling that the real contact with myself is being established […]. Really a freedom of feeling. […] And I've fallen in love again […] Painting gives form to what is coming loose, what lives somewhere inside me. Together with the swimming, nicely physical. Yes, that's the*

movement I'm in. And I am really super grateful for that. (PV)

Too much pressure from the outside world is often contra-productive. In the narratives, opposition often involved resisting pressures by the environment, for example by mental health professionals trying to force the person into a certain direction, or following another time perspective.

In the case of HM the hospital proposed a resocialisation schedule of four days home and three days at the ward. *I had to go back on Thursday evening with the bus to S. [psychiatric hospital JPW], because I had to stay there for three days. They took me home; I pulled out the phone plug, went to bed, and never returned to the hospital. I just did what I pleased!* (HM)

In the reorientation phase, the life review or analysis of the own biography requires sufficient time. Many participants in this study talked about the time they needed
* to gain insights; to understand what was happening or what had happened;
* to 'wake up', meaning to become aware of their situation, to realise what the current situation is;
* to experiment with what can and cannot be done with the disability; people often speak about finding new borders again; and
* to develop a new perspective on their past, their self-image and their future

Time is also needed for setting steps, having new experiences and learning skills. All this is required for the development of strengths and self-confidence.

Transitions

The study gives insight into the influences on the transitions between the different phases of stabilisation, reorientation and reintegration. In Table 3.3, the factors of transition that were identified are listed in the first column. The second column lists what this factor has induced. In the last column the result of this transition is given.

Transitions may be characterised by changing from a passive mode into an active mode in a specific life domain. This active mode may first be an internal psychological shift. People develop the desire to change something (for the better). A next step is to transform this desire into operant behaviour. There are many possible factors that may lead to a transition, but in this study the following come to the fore:
- Oppressing circumstances or survival after a suicide attempt
- People or environments providing rest, safety, reassurance and affirmation
- Medication and psychotherapy that enabled the person to acquire more self-control and that helped him or her to develop a new perspective.
- A focus on something positive (either by the person him- or herself or by others), for example focusing consciously on something one likes, developing and/or using a talent, being acknowledged by others for personal qualities
- Becoming connected to a community

Table 3.3: Factors of transition

Factor	*Induced*	*Result*
Oppressing circumstances	Resistance	Change of circumstances; better understanding; awareness of strength
Survival after a suicide attempt	Self-reflection; awareness; communication with others	Change of perspective; will to live
Having a calm person around; reassurance by others	Reduction of nervousness and anxiety; someone to hold on to	Relaxation; more stability and self-control, creation of space to work towards better future
Right medication	Reduction of anxiety; being able to think more clearly	More stability and self-control
Psychotherapy and personal attention	Self-control; self-reflection; awareness	Creation of a perspective
Focusing on something positive (person him- or herself)	Transition from a negative towards a positive pole	Creation of a perspective
Focusing on something positive (others)	Reduction of anxiety	More confidence; use of qualities
Becoming connected to a community	Social contacts; social structure; skills to be used again	Sense of belonging; meaningful roles and activities; usefulness
Discovering a talent	Self-confidence; shift of focus; goal orientation	Recognition; usefulness; empowerment

From the stories it became clear that transitions are sometimes induced by people themselves, and sometimes by others or by changing circumstances. In all cases, people have to make the actual transition themselves. How an internal change of mind or a transition to move into action actually takes place remains to be clarified. Important elements may however be an increasing degree of energy, self-control, self-confidence and the development of a new perspective. In addition, another important element is opportunities that arise or are proposed. If the person has a certain degree of self-control and self-confidence and enough basic energy, opportunities are more likely to be taken. If they are taken, this contributes to the further development of a future perspective. If a certain personal constitution is paired with the right support and opportunities for improvement or development, a spiral movement towards recovery can be initiated.

Changes in the process of recovery

Changing from a passive mode into an active mode

I describe a number of transitional phenomena in the process of recovery. One of them is that the person is changing from a passive mode into an active mode. He is not 'undergoing' anymore (i.e. being a passive recipient of care; being in a patient role), but is becoming an 'actor'. This leads to a drastic change in personal perspective.

In a number of cases of the participants in the study, transition took place in a very bad situation, a situation that could not become any worse. People make a decision to do

something about the situation. They took action when they were for example placed in an isolation room or faced a 'life sentence' – a referral to a 'chronic ward'.

> *Then I spent five days in the isolation room, yes, and that is the worst time of my life […] I thought: I have to put my shoulders to the wheel. Because otherwise I will never come out. I have to work on it myself. From that moment on, I switched over and put my shoulder to the wheel.* (BE)
>
> *Then they wanted to take me to X. That's a ward for chronic patients. And there I could live for a number of years. Yeah, I didn't like the idea at all. Then I tried to commit suicide.* (KP)

Others had miraculously survived a suicide attempt, and saw this as a sign that 'life has still something in store'.

> *It is actually a wonder that I am sitting here, that I can talk, that I can walk. […] Nobody survives a fall like this, but I did. So, the fact that I survived has given me a lot of power.* (FJ)

Another transitional phenomenon is the acceptance that there is something wrong and consequently acknowledging that help is needed.

> *The first step for people is that they realise that something is not right, that something is wrong. And that they need help. That's a matter of admitting and accepting. That is just the first step. And the most difficult one.* (FJ)
>
> *You are psychotic and you hear voices. And you are walking through the village in a funny way. […] I was very sad about it; why should this happen to me? […] When I had accepted things the way they are, I was thinking by myself: I have to make something out of my life, like I think it is OK.* (KP)

Changing the stance from a passive witness to that of an actor means that a *goal* is set. A primary goal is to get relief from the extreme stress the situation brings. It is aimed at changing the negative circumstances in which the person finds him- or herself. The *goal orientation* provides the motivation for action. It is a short-term perspective, with pure individual interests. It seems to be associated with a basic instinct for survival. In a number of cases, this transition is associated with both a struggle within and a struggle with the outside world. In the literature, this struggle is often associated with the notion of *resilience* (Deegan, 2002).

> *Apparently one finds the strength in that situation to say: I have to come out of this.* (BE)

A number of stories show that people make a transition after they appear responsive to messages others bring to them. These messages usually contain an appeal to make a positive change, or an appeal to hidden strengths or talents. Responsiveness is expressed by sentences such as "I got insight", "I became aware of ..." or "I woke up".

> *During the second admission at S [psychiatric hospital JPW], in conversations with the psychiatrist and the senior nurse, actually I woke up. I thought by myself: what am I doing? […] They said to me, you are capable of much more than you show. You approach yourself so negatively. You have much more than you show. They wanted to pull it out of me …*
> *Up to a given moment, I said: Damned, maybe they are right. I will start thinking more positively about things and ... Because I was thinking every morning: How miserable am I. What a hell I have in my head. But you can also think differently. I don't have a hell in my head, and I like to have a bite to eat. And I am going to have a nice little walk. There is a saying: To change one's tune, but really you have to do that to yourself. But if you're really ill, than you can't do that.* (HM)

The reorientation phase can be considered a phase of transition by itself. It is a phase that is characterised by a growing awareness of the actual situation. In the beginning of this phase, the emphasis lies on looking back, going over what has happened and exploring the impact. Many participants became depressive during this phase and went through a process of grief.

> *I didn't want anything. I wanted to lie in my bed; preferably to sleep it off [...]. I lay on my bed for eight months.* (NS)

> *You cannot reduce the emotional pain. It is just there. You have to give it space. Look, I was going through a process of grief, of understanding that I am ill. That's quite a shock.* (NS)

In seven out of the thirteen stories, awareness developed only after a number of crisis situations or admissions. This was for example the case with HM who, after a number of admissions, developed the insight that he himself had to come to action in order to change his situation. Also KP, who after his suicide attempt, signalling his environment that he did not want to spend the rest of his life in a chronic ward, came to the conclusion that he himself had to take initiative to change his life, and that he had to stop to depend on others to decide what to do.

> *They said: What do you want with your life? What do you want to achieve with this? Then I started to think for myself what I wanted in life.* (KP)

Depression is often caused by a feeling that the very foundation of existence has disappeared or has become awfully fragile. Status is reduced dramatically and many former roles and ambitions collapse.

> *At first, the feeling was very bad. I am nothing. I don't have anybody. Nothing to hold on to. I had no job, no relationship, thank god a network of friends and relatives, but deep down the feeling of I am nothing and I am not able of anything … So in fact it is only grief and anger, grief, anger, yes, the whole shit.* (EH)

Anchor points

In order to be able to make a transition, it seems to be important to have one or more anchor points – beacons of hope to hold on to. The study shows numerous examples.

> *At a certain moment I said to myself: "Is there something you like to do?" I thought, well it seems fun to smoke a jo int and to watch television. […] Then I started to find [...] a favourite programme for every day. And every time I left my bed a little bit longer. I had not done this for eight months – looking forward to something.* (NS)

> *My mate saw my qualities, and named them to me. That was wonderful, because in fact I was scared to do anything.* (EH)

> *Then he gave me a year of psychotherapy […]. This meant a lot to me, an awful lot. […] After three months I got some grip. "You'll get some extra therapy", he said. "We are just going to work in the direction of the future." I got a lot of attention, a lot of professional help. This went very well. In the beginning I thought, I will never manage, never. I looked up to it tremendously. And suddenly I got a perspective.* (GK)

> *I relied very much on what others told me. The psychiatrist who said: "It is going all right, have patience". Reassurance was very important. I always looked for reassurance, and always got it. Until, at a certain moment, I was able to create my own reassurance. But this took me more than a year.* (PV)

Orientation has two focus points: the inner self and the outside world. Although there is interaction between these points, the energy first goes to the inner world. Later on in this phase, when the narrative has been

reconstructed to a certain extent as a personal basis to stand on, the emphasis shifts to the position in the social environment.

From personal to social recovery

At the end of the reorientation, the start of the reintegration phase, the goal orientation becomes more long-term oriented and more oriented towards 'inclusion'. The actual steps that constitute a change can be considered another type of transition. They are aimed at becoming part of the social world and at starting to fulfil meaningful social roles, for example in the domain of work.

> *I started looking for a job. Especially work that I find useful. And regardless of whether it had status or not, I wanted it to be meaningful to me, and nice.* (EH)

At a certain point, often based on only a small foundation of confidence or trust, steps are taken to re-establish connections with the 'normal world'. This may require considerable energy.

> *It was really difficult for me to go somewhere by train, for example. This was on the edge of being too hard. I did it occasionally when it was really necessary. But my life usually consisted of going to paint in the city, physiotherapy, swimming, and being here [at home JPW].* (PV)

> *At a certain moment I took up studying again. And suddenly I was in a very bad shape again. It turned out that when I was in class, my 'school bullying' history came up. I came in that class and everything came back again. I didn't feel safe.* (MR)

> *Very slowly it evolved in a sense that I became more at ease. I started to make friends quite easily. That was a nice side of me. I always had the skill to socialise, and that has often been my salvation, that I always found people around me. So, now I felt part of a kind of social community again.* (AD)

Sometimes, this transition, actually moving into action, comes as a surprise to the person.

> In the story of GK, for example, he quite suddenly discovered his talent to write poetry. He moved from a passive mode to an active mode. Writing poems had multiple meanings for him. It affirmed a part of his identity. It increased his confidence. For the first time in his life he had a clear personal orientation. This goal orientation had a great positive impact. It also provided more stability. It contributed to the development of the inner self, and also provided a connection to the outside world. His talents were recognised by others. Writing and publishing poetry provided him with identity and status in the eyes of the outside world. So, a transition took place both within the inside world as well as from the inside to the outside world. And at the same time, it was a transition towards reintegration. Being a poet and publishing poetry led to valued contributions to society and to social participation.

A transition or turning point may take place if on the one hand there is a certain readiness from the person's side to make a change and on the other hand an opportunity appears in the same time perspective. This opportunity might be offered by a person, but may also be offered in the form of a job or housing opportunity.

> *This labour consultant helped me to get the job I have now. He introduced me to this horticulture. I started with two days, and then after a couple of months two and a half days, and then three … Gradually building. Until now that I'm working four whole days. The most important point was to let me go along. I had to find out for myself what I was capable of.* (KP)

3.6 Personal niche: Taking care of vulnerability

Adapting life to the vulnerability is what I describe as a 'personal task', or a daily challenge. Some people regard the vulnerability as a burden; others consider it a blessing, stating that the process of dealing with the disability had enriched their life. One way or another, every person has to find a way to cope with self-impeding factors. Impairments have distorted the identity or the conception of the self. Here the task is to reconstruct an integrated sense of self, where the disability is part of (see paragraph 3.7).

From my analysis the concept of the personal niche emerged. Simply put: a personal niche is a space in which the person feels at ease.

Box 3.1 The meaning of niche

There are different meanings of the term niche, which make it suitable for use in the framework of this study. Niche comes from the Old French expression '*nichier*', to nest (from Vulgar Latin 'nīdicāre', from Latin nīdus – nest). In ecology, niche refers to a particular area within a habitat occupied by an organism. This area is adapted to the needs of a certain species. A good habitat contains the resources that enable a species to survive, to remain healthy, to reproduce and to co-exist with other species. Since habitats tend to evolve, species have to adapt all the time. But also, the behaviour of the species itself influences and changes the habitat. Niche also means a "shallow recess in a wall" a protected area where for example a fragile plant can grow and flower. Finally, another meaning of the term niche is "a situation or activity specially suited to a person's interests, abilities, or nature" – as in the expression "He has found his niche in life" (Random House, 2005).

As our understanding of recovery grows, we see that people construct a 'nest', a safe personal habitat, a protected area, which enables them to take care of themselves, and specifically of their vulnerability, and which serves as a base from where to 'spread the wings and fly', enabling social participation. Every person strives to find his or her niche in life. For people with psychiatric disabilities, this has a double meaning: finding a personal niche, and finding social niches, or, in ecological terms, to relate the own 'particular area' to a habitat.

I define a personal niche primarily as a psychological zone in and through which a person feels reasonably comfortable and remains in a state of balance. It is a constellation of mechanisms of self-regulation with regard to stress and energy management. A number of characteristics of a personal niche can be determined. A personal niche
- is individual and unique to the person;
- is a protected environment; it is safe and offers security to the person;
- is owned and directed by the person him- or herself; and
- is non-interruptible.

The psychological zone includes experiencing personal safety, being able to cognitively manage boundaries, and being able to respond to environmental stress factors. The personal niche also has physical and environmental dimensions. The physical dimension is related to

stress as experienced by psychiatric symptomatology such as delusions and hallucinations, or physiological phenomena such as headaches, and can also be induced by external factors that cause stress. Within the personal niche, stress is absent or reduced to an acceptable level. Psychological aspects are also related to physical and environmental aspects. Physical wellbeing includes being able to get enough rest or sleep and the absence of anxiety or depression or these being present at a manageable level. It often requires active physical and psychological efforts to maintain a balance.

Environmental aspects include physical surroundings such as having a primary territory like a room or an apartment that can be fully controlled by the person, and the positive influence of external factors such as support from other people. Participation in social environments should match as much as possible with the requirements of the personal niche.

A personal niche has to be created and maintained. This often requires considerable effort. The person should discover his or her personal boundaries and experience what works and what does not work to keep within these boundaries.

Recognition of the task of managing the personal niche, both by the person him- or herself and by others around him or her, will acknowledge the disability and the efforts the person has to make to remain in control. By analysing the narratives, personal niches and the tasks connected to managing these niches were revealed. A clear example comes from the story of GK.

> At the time of the study, GK was 36 years old. At the age of 16, he became psychotic, following a minor surgery after which he had not been able to sleep for 10 days. In the years before this event, a number of people around him had died. One of them was his grandfather, with whom he had a close relationship. For more than 15 years he was in and out of hospital. He was considered as one of the most 'difficult' patients, often aggressive, and was often placed in closed wards and isolation rooms. His story shows that since his puberty, various beloved family members died, and thus the theme of life and death is a thread in his narrative. In addition, during his years in the hospital he experienced a number of deaths, some of them violent, among his fellow patients. On a symbolic level, for GK 'death' represents being alone, not being a part of the world, a state of apathy, immobility and exclusion. 'Life' represents a state of openness and belonging to a community. 'Life' expresses possibilities and meaningfulness. His personal task was to keep the middle between life and death. Coming too close to the 'death pole' implied a state of psychosis, disintegration and extreme loneliness. Coming too close to the 'life pole' could lead to chaos and 'getting lost in the world'. This may give a sling back to the death pole. In-between is the 'personal space' GK had to manage as his personal niche. This personal niche is a 'space in-between', a psychologically safe zone. In this zone, he was in control. Once he passed a boundary, either to the 'death' side or the 'life' side, it could become dangerous. Managing the personal space implied living in a state of 'bonded freedom'. GK was free to move around and able to maintain a reasonable quality of life, but in return he had to refrain from 'going over the border', as the pressure lies at the borders of the personal space. In his case it meant he avoided groups of people and stayed at home most of the time.
>
> He literally expressed that in certain circumstances he felt like he was 'swelling up' and going to suffocate. This may relate back to his experience after the nose surgery,

when he felt that he could not breathe and feared he would die. Suffocating is associated with dying.

When experiencing tension such as these, it helps to rest. During the majority of the time he spent in hospital, rest was something he could not do much, as he had to go to therapy, participate in activities in the day centre, and so on. He was dependent on others to grant him rest. If rest was not possible, he often 'exploded' – with all the consequences. Now, he is able to direct this himself. Since he was in control, he was able to remain stable.

Managing the personal niche requires an active stand. In the past, passiveness in people diagnosed with schizophrenia was often classified as 'negative symptomatology' or sometimes associated with depression. The analysis of a number of narratives in this study suggests that in fact people *actively manage* their vulnerability, which requires considerable energy. No wonder many people need a lot of sleep.

GK was a very energetic person, but he had to use part of his energy *not* to engage in things that might lead him to the danger area. Rest is a *performance.* For vulnerable people like GK, it is not the absence of stress which is pursued, but how they are the least troubled by stress.

For GK, one of the qualities of his personal niche was 'rest'. Rest gave him control and safety. For GK, the house in which he lived provided environmental safety, because it was rather quiet and the other residents, the staff and the daily routines were familiar to him. It was also important that he remained in control. The fact that he shared this control with others in the house was not a disadvantage, but part of his conception of safety.

As evident in nearly all the stories, an important aspect of personal-space management is to manage *energy*. In some cases, people have little energy while others have a lot; some have little while others have more power, which is difficult to handle, and can easily lead to a misbalance. In these cases, power needs to be tamed and managed.

Finding and acknowledging the factors that cause stress and knowing one's vulnerability provide a good basis for learning how to manage stress and vulnerability. In line with the findings of the review study in the previous chapter, it seems that a certain insight into phenomena connected to the disease, the disability or vulnerability is necessary to learn how to handle it. In addition, experiencing in real life situations what the structure is of one's own sensitivity and how to protect one's personal space is equally important. Managing the personal niche means knowing what the borders of the niche are. It requires time and experimentation to find these borders. Once people have discovered their borders, they offer a structure for maintaining a balance.

SW described his struggle with his manic-depressive disorder. He knew not to cross certain borders, but at the same time these borders had a strong attraction. It was as if he was constantly attracted by danger. Being 'on the edge' gave him a wonderful feeling, but at the same time he knew that one step further could cast him into a ravine.

Being manic is clearly that you pass your borders; you are also really looking for the edges. Almost consciously. In relations with people, you look for the boundaries. You

explore the borders of yourself. It really feels like a childish urge, in which you in fact are asking to be withheld. But wee the one who is doing this. I smack them, so to speak, not physically, but with words I strike out right and left. […] If I am manic, I am verbally more gifted than in my normal life. I get things done. Only, it does not sustain. I am building on quicksand, but it feels wonderful. (SW)

Subjectively, the space of the niche may be experienced as small or large. Without given borders, the space becomes endless and difficult to take care of. People often wish that their niche was larger, because this would give them more possibilities in their social life. They experiment to find ways to extend their moving space, for example by changing their medication. Others are satisfied with their niche and maintain it with care as it is.

Managing the personal space also means that social relationships and events have to be managed to ensure that they do not become a threat (see also paragraph 3.9 about social niches). This requires competences of anticipating adequately on social situations. Sometimes, events or the interaction with other people are overwhelming, and people may have a relapse. Often, an important element of recovery is that people learn to deal with events and social interactions that cause stress. It is clear that taking care of the personal space requires, besides 'internal management', also considerable 'relationship management'.[11] In this study, it becomes clear that people use many different coping competences.[12] The challenge is to discover efficient strategies and to learn how to use them. A condition for self-control is that the individual is able to monitor his or her own behaviour and the situations that he or she wants to control. In this regard it is important how the person perceives him- or herself, his or her environment and situations or events. A situation is stressful depending on how the person interprets the situation and assigns meaning to it.

In the recovery literature, from a psychological point of view, the development of effective coping strategies is considered an important condition for further growth.[13]

[11] This seems to be connected to the old concept of 'expressed emotion' (Kuipers & Bebbington, 1988). Studies show that an environment that puts too much emotional pressure on the person (whether it is the family or mental health staff), regardless of how well it is intended, could cause a relapse (Butzlaff & Hooley, 1999; Moore, Ball & Kuipers, 1992). Since the 1990s, the 'management' of expressed emotions has become a field of attention for professionals and carers, as is recently the case in the care for people with a first-episode psychosis (Raune, Kuipers & Bebbington, 2004). However, my study highlights the perspective of the person him- or herself, showing that learning to actively handle potential threatening social situations is important in order to handle the vulnerability, and is part of a recovery process. Personal psychological and social factors are intertwined, which is expressed in the notion of psychosocial vulnerability and the vulnerability-stress-coping-competence model (Nuechterlein *et al*., 1999).

[12] This is consistent with the literature on coping strategies, which shows that many people have a strong motivation to manage their disability, and have the capability to do so by coming up with creative and effective strategies. There are numerous coping strategies reported in the literature. Hogan (1994) mentions a list of over 1 500 coping strategies used. Many of them were encountered in the current study. Coping strategies include self-monitoring (Breier & Strauss, 1983; Leete, 1989; Lovejoy, 1984), self-instruction (Breier & Strauss, 1983), getting into a routine (Anonymous, 1986; Leete, 1989; Walker, 1986), increased or decreased activity (Breier & Strauss, 1983; Deegan, 1988; Leete, 1989; Walker, 1986; Yagi, Kinoshita & Kanba, 1992), prayer (Cohen & Berk, 1985) and seeking out support from others (Breier & Strauss, 1984; Cohen & Berk, 1985, Deegan, 1988; Leete, 1989; Lovejoy, 1984; Walker, 1986). The various strategies that can be employed can be classified as cognitive strategies, behavioural strategies, sensorial strategies and physiological strategies.

[13] It is not yet clear how types of coping strategies correspond with clients' characteristics or with situational factors. Studies give different results (Appelo & Slooff, 1993; Breier & Strauss, 1983; Carr, 1988; Cohen & Berk,

3.7 The recovery of the self

Reconstructing a durable sense of self

Besides taking care of the vulnerability, another task in recovery processes is to reconstruct an integrated and durable sense of self.[14] This identity is not dominated by the disability, although having a disability is a part of it. Besides the negative consequences of the disability, the recovery process entails discovering and (re)affirming positive qualities as a basis to create new perspectives. A number of qualitative and ethnographic studies on people with schizophrenia support the significance of a durable sense of self in recovery (Davidson & Strauss, 1992; Deegan, 1993; Estroff, 1989; Davidson, 2003; Sells, Stayner and Davidson, 2004). A durable sense of self refers to an understanding of who one truly is as distinct from an illness that one has and the stigmatisation one may endure because of it. This includes recognition of one's own perceived positive qualities as provided, for example, by experiences of self-esteem or a sense of internal control, as well as self-perceived limitations and areas for future growth.

The self becomes more integrated and durable when someone is able to take care of the personal niche. Or, to put it the other way round: Knowing and handling the personal niche contribute to the development and reinforcement of the self.

The narratives in this study confirm that becoming (seriously/chronically) ill can be regarded as a serious "biographical disruption", as Bury (1991, p.167) calls it. Bury characterises this disruption as an attack on the identity of a person. Two types of meaning become important: firstly the meaning of the consequences of the disease in daily life, and secondly the symbolic meaning of being ill and the specific illness, and the images and social reactions that are evoked thereby. The illness has to be placed in the framework of the biography. Explanations and legitimisations become important. In this process of adaptation,

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1985; McCandless-Glincher *et al*., 1986; Van den Bosch, 1993; Wiedl, 1994). Van Weeghel (1995) stipulates that the different outcomes can be attributed to either differences in research methodology and research groups or the extensiveness of the spectrum of coping strategies. He mentions a few studies that illustrate that clients who have a job use more active, problem-oriented strategies. A motivational factor seems to play an important role: If a person is very eager to keep his or her job, he or she tends to use more active strategies because they are more effective in beating unwanted disturbing symptoms (Cohen & Berk, 1985; Folkman & Lazarus, 1980; Schwarz & Stone, 1993). Using more active, problem-solving coping strategies implies being competent to learn and use skills. This general competence includes being able to (self-) monitor symptoms and stress factors and to respond to them in an adequate way.

[14] Sedikides and Gregg (2003) define the self as "the totality of interrelated yet distinct psychological phenomena that either underlie, causally interact with, or depend upon reflexive consciousness" (p. 110). This definition describes the self as both a set of properties and a set of processes, each of which can be conceptualised and defined. These are fairly complex and operate predominantly within the social world. However, the self can also be regarded from a phenomenological point of view. The self is then related to a growing consciousness of, as Ricoeur (1950, 56-57) points out, being the author of my actions, and this kind of awareness often comes about as actions are reflected in the presence of others. The self is intersubjectively mediated by social relationships. In philosophical terms self can be defined in terms of will and agency (Taylor, 1989). I know I am a person because I decide to do something and I do it. Such a definition certainly explains the loss of self experienced by persons in the grips of a psychosis. In psychosis, alternate realities present themselves as plausible, and the normal sense of temporal continuity we generally expect between various aspects of our self-experience may all but disappear. We might experience the ordinary and the extraordinary simultaneously, or encounter the extraordinary so vividly that awareness of the ordinary is temporarily lost (Kelcourse, 2008).

different styles or strategies of dealing with the illness and its consequences can be found. These styles are partly related to personal characteristics and social background, and are partly a result of an ongoing self-dialogue and interaction with others.

Life reviewing is one way to work on this task. The other way is to experiment with activities and social interactions. The special challenge is to rediscover the basic human qualities and capacities that have been buried under psychopathology and hospitalisation effects. The task is to 'dig out' the hidden or alienated parts. Some people manage to do this to a great extent on the basis of their own strengths, but in most of the narratives in my study, others, such as mental health professionals and peers, formed an essential resource.

In a number of stories a combination of particular circumstances during childhood, sometimes (apparently) in combination with certain personality traits, caused some kind of vulnerable predisposition for the psychiatric illness occurring later on. But the main separation occurs through the occurrence of the illness, hospitalisation and the disabilities resulting from this. The process of recovery is a process of reattachment. Different phenomena of anxiety, as described by Bowlby (1969; 1973; 1980), can also be recognised, such as the anxiety to reattach, based on the fear that this might again result in loss, and abandonment anxiety, the fear to lose the bond once attachment has been achieved. It is understandable that people develop a sense of self that enables them to connect to others in a way that provides a certain protection from losing themselves.[15]

The notion of the self is connected to many different other notions such as self-confidence and autonomy. Self-confidence can only exist if there is a perception of personal strengths. Autonomy is connected to the awareness of being able to take care of the self, of being self-reliant, of being able to make one's own decisions. In essence, self-confidence and autonomy are connected to experiencing oneself as stable and continuous. This is mediated through the interaction with others.

Reorientation: The process of life reviewing

A central process in the reorientation phase is the process of life reviewing. All the participants in the study were or had been working on (re)constructing their narrative. Corin and Lauzon (1994, p. 25) call this "reworking his or her personal history and sense of temporality". This might be understood as recasting one's past in a positive relation to the present, in which it becomes possible to reconcile past and current problems, both personal and social. It forms a significant challenge to find ways in which one's present situation can be viewed in favourable terms and connected in a meaningful, contiguous way to one's past.

A number of people in my study used reminiscence to (re)constitute their identity and their sense of self. The aim was to discover meaning and continuity. Others drew on past experiences to cope with their problems. Some people reported periods in their life when they were bitter about what had happened to them, and preoccupied with unresolved, disturbing events in the past. A number of people turned their narrative into an instructive story and were able to inform or teach others about aspects of recovery. This occurs when people become active in the consumer or recovery movement.

[15] In the narratives a number of different forms of attachment came to the fore, including the attachment to a psychiatric institution, which fulfilled the function of a 'safe haven'.

Box 3.2 Life review

Narrative psychology provides insights into the process of life reviewing. A life review is one of the forms of reminiscence.[16] This notion was used for the first time by Butler (1963) when he noted that many people in the last stage of their lives struggled with their life story, trying to pinpoint the meaning of important events in their life. He regarded the life review as a spontaneous or naturally occurring process that is "characterised by the progressive return to consciousness of past experiences, and, particularly, the resurgence of unresolved conflicts" (p. 66, cited in Bohlmeijer, 2007b, p. 32). In his later work, Butler (1980) says the main developmental task is to "clarify, deepen and find use of what one has already obtained in a lifetime of learning and adapting" (p. 531, cited in Bohlmeijer, 2007b, p. 32). In the 1990s, researchers linked the rather general ideas of reminiscence to psychosocial theories of adaptation, stress and coping and developed several therapeutic applications, extending reminiscence throughout the life span. Bohlmeijer (2007b) reviewed the literature on the life review and found that younger people that are confronted with a chronic illness or other serious life event may also feel the need to look back on their lives extensively.

In the literature, different explanations are given for the effective ingredients of a life review (Bohlmeijer, 2007a; 2007b):
1. Emotion regulation. By means of a life review, memories are actively recalled. Memories may refer to painful and emotional experiences, such as experiences of loss and conflicts with significant people that are associated with feelings of shame, guilt or sorrow. Life reviews help to process experiences of loss (Silver, 1995), to discuss conflicts and emotions, and to solve these or to give them a place in one's life (Watt & Cappeliez, 1995; Garland & Garland, 2001).
2. Evaluation and connotative meaning. Life reviews help people to dwell on the meaning of experiences and to evaluate them. In this way, people can find answers to questions with regard to meaning and the sense of their own life. When this is done successfully, a feeling of integrity develops (Haight, 1988; 1992; Wong, 1995). Erikson defines integrity as the acceptance and acknowledgement of the own unique life course, as something which had to occur in a certain way (Erikson, 1959).

Bohlmeijer (2007a) describes a method that links the life review with elements of narrative therapy. Narrative therapy offers a framework in which problem stories about the own life, often leading to depressive complaints, can be turned into empowering stories. Some stories in my study describe the same phenomenon, using different methods such as multilogue groups (Mölders, 2003; 2004), recovery groups (Boevink, 2009) or psychotherapy.

Making use of language, i.e. talking, telling and being able to express oneself, seems to be an important competence for life reviewing. A number of participants reported that 'having learned to speak' was crucial to them in order to be able to talk about their experiences.

[16] Reminiscence can have many different functions. A factor analysis by Webster (1994) identified eight functions: boredom reduction, death preparation, identity, problem solving, conversation, intimacy maintenance, bitterness revival and teaching/informing.

Some people in my study had made a remarkable switch from a kind of negative, psychopathological way of dealing with their experience to a positive way. This turning point was often initialised by a form of life review. [17]

A number of the narratives in the study show that life reviewing is often mediated by dialogue, mostly with mental health professionals.[18] In the reorientation phase, three forms of orientation can be distinguished: looking back, looking at the present and looking forward. Basic cognitive competences are related to the ability to think in terms of a time perspective. A basic psychological competence is to compare and relate events, and to have a certain understanding of the relation between own behaviour, circumstances and events. All the participants in this study had these abilities, but there certainly will be others who have cognitive impairments that disable them with regard to these competences. They need others to help them picture their life and discover purpose and meaning.[19]

In looking back, facts and emotions are processed. Often there is a process of mourning, a process of trying to cope with what has happened and to find meaning in it (Wilken, 2006).[20] A number of people in my study only articulated this mourning process in retrospective. When they were in the middle of the situations, the phenomena were easily confused with reactions to hospitalisation or with psychopathology.

In the literature, four processes of reminiscence are mentioned: preserving self-identity and self-continuity; enhancing meaning in life and coherence; preserving a sense of mastery; and promoting acceptance and reconciliation (Bohlmeijer, 2007b). In the narratives in this study, all four aspects are recognised. One of the ways in which a personal identity is formed is by the awareness of how the self has changed over time (Baumeister, 1986).

Identity can be seen as an authentic biography that gives answers to questions such as Where am I coming from?; Where am I now? and Where am I going? (Bluck, Alea, Habermas & Rubin, 2005; Giddens, 1991). Giddens states that a person's identity is not found in

[17] Butler (1980) distinguishes between adaptive and constructive manifestations of life review as well as psychopathological manifestations. The adaptive variant is described as a revision of former life experiences and their significance. This is often accompanied by feelings of nostalgia or regret, but are usually characterised by increasing insight into and acceptance of the own life. Sometimes a reorganisation of the personality takes place. The pathological manifestation is described as a constant preoccupation with the past. This may lead to severe depression, intense feelings of guilt and feelings of panic.

[18] A specific way of life reviewing with people with a long history in psychiatry is the method of rehistorisation, as used by the Dutch rehabilitation psychiatrist Petry (2003; 2005).

[19] A number of authors draw attention to contextual factors in reminiscence. One factor is the influence of others in the process of reminiscence, for example the opinion or experiences of others (professionals, family members, peers). Another factor may be the cultural context and social or group norms (Parker, 1995; Wallace, 1992). Molinari, Boeve, Kunik and Snow-Turek (1999) found that it made a difference whether people live in an institution or in the community. Generally, in narrative psychology, it is stressed that telling one's life story is a process of co-construction in which others influence the content (Adams, Smith, Pasupathi & Vitolo, 2002; Bohlmeijer, 2007b; Marsh & Tversky, 2004).

[20] This is consistent with findings in the literature on mourning processes of people who have experienced a chronic illness. Imao (2004, p. 96) writes in this regard: "Chronic illness is a form of the 'object loss'. Patients with chronic illness undergo various changes, including such 'object losses' as bodily functions, social constraints, etc. Patients accept their losses by going through the mourning process. Psychological reconstruction, as a function of the mourning process would be the basis for patients' efforts to adjust to life with chronic illness".

behaviour but "in the capacity to keep a particular narrative going" (1994, p. 54). In some stories used in this study, the narrative seemed to be frozen at a certain moment in time, which also led to a loss of identity – a reduction to an identity of for example a psychiatric patient. By unfreezing the narrative, identity could be revived. Telling and retelling the story of one's life contributes to the uncovering of identity and the revealing of the self. Many participants in this study expressed that being able to tell their story to the researcher also helped them in their process. A specific result of life reviewing and determining the current status of life is that it helps people to define their own safe niche and gives them the strengths to take care of it.

Reconstruction of identity

The work of Bowlby (1969; 1973; 1980) can be used to explain the importance of (re)constructing a durable sense, both from the perspective of internal control and from the perspective of connecting to the external world. The strength of Bowlby's theory lies in its articulation of an individual's need for secure attachment for its own sake, for the love and reliability it provides, and for its own 'safe haven'. Primary attachment promotes a sense of security and self-esteem that ultimately provides the foundation on which the individual will form lasting, secure and loving relationships in adult life. The psychosocial environment in infancy and childhood paves the way for successful development that continues through adulthood. For Bowlby, the capacity for intimacy in adult life is not a given, but is instead the result of complex dynamic forces involving attachment, loss and reattachment. Early childhood emotional development is widely recognised as a critical period of development not only for emotional and cognitive development but for health as well. Although the stories in my study do not reveal much about early childhood emotional development, one could say that, by a combination of factors, considerable 'loss' had been experienced, with a high emotional impact.

> *I had the very strong feeling deep inside that I was nobody anymore. I had nothing to go by, no work, no relationship.* (EH)

Studies show that a temporal orientation of stability of the self is related to subjective wellbeing (Keyes, 2000). This may support the idea that experiences of wellbeing in the past, for example good memories of the childhood, would help people who encounter dramatic disruptions in their identity, for instance by a psychotic disorder, to restore a sense of self more easily than people who have mostly negative memories.

Autobiographical memory has the function to provide continuity of the self. A positive valuation of the self contributes to this, for example identifying what has been successful, and which strengths are present in the personality or were developed during the life span. Several authors state that identity is also based on a commitment to stable values and ideas (Erikson, 1959; Niemeyer & Metzler, 1994).

> *My sign of the Zodiac is Aries […] I am very persistent, and you need this to pick up.* (BE)

> *What has helped me a lot is that I am quite good at relating to people. Others regard me as reliable, that I know how to listen well. I am always interested in others. And that helps very much to make friends. My verbal abilities have always been strong.* (AD)

Identity is also based on awareness of how a person (and his or her self) has changed over time (Baumeister, 1986). The following are

examples from the narratives about the process of life reviewing:

> *And then I had one and a half years of day treatment. This was very helpful. Actually then I could very slowly look back, to see all the things that had actually happened.* (EH)

> *Yes, we have been spitting through my life, to find out how it came that I have been damaged so very much. Yes, and then you see that you don't come from a normal family. That pretty much was wrong in the past. And this has formed you to what you are now. Now I have much more understanding of myself and my situation.* (FJ)

> *What really helped me in my reorientation process was this multilogue group. [...] Yes, at a certain moment I went there. And the first time I was there I said nothing. Only at the end, everybody gets the opportunity to say something, you don't have to say anything, but I think I said that I'd liked it, but I felt a lump in my throat, you know. Yes, I was quite emotional, and now I know reasonably well to talk, also about the separation, but I really processed it there. By telling about it. Hearing myself telling it is also a process.* (BE)

Some participants in my study made a remarkable switch from a kind of negative, psychopathological way of dealing with their experience to a positive way. This turning point is often initialised by a form of life review.

This was for example the case in the story of HM, which I used before in the box about changing from a passive mode into an active mode:

> *I was thinking every morning: How miserable am I. What a hell I have in my head. […] They said: "You have been able to get through tough times. You have always been working, taking care of yourself. You have been married, you had a good marriage. You have two nice children. You owe this to yourself. You have renovated your house, did the tiles, you have built the bar". These are all things, they said, you have been doing all by yourself. […] Up to a given moment, I said: Damned, maybe they are right. I will start thinking more positively about things and ... I don't have a hell in my head, and I like to have a bite to eat. And I am going to have a nice little walk. There is a saying: to change one's tune, but really you have to do that to yourself.* (HM)

In the story of RH, others played an important role. They were in fact reviewing his life for him, articulating positive sides. At a certain moment, he accepted and internalised this.

Aspects of mourning are illustrated in the next examples.

> *I think I was really in deep, deep mourning. And I could not name it, because of course, I had to set goals, because I had to get out there, while basically the feeling was very much … I am nothing; I am nobody anymore, nothing to hold on, no work and no relationship anymore. So it was in fact only mourning, anger, mourning, anger, the whole bunch.* (EH)

> RL stated that having this disease meant that he had to lower the demands made to himself. This made him sad sometimes, but he tried to be positive about it. *Seeing the positive side of things is pretty tough! Everything has two sides.* He talked about developing a new self-image: *You have to look very different[ly] at yourself. You can't compare yourself to an average person.* It revolves around accepting yourself with your identity (including a disability). *And slowly going to think: I am quite a guy.* (RL)

In the reconstruction of the identity, the participants altered their perception of what is important in life.

> *In the past I fussed about the nice car of my neighbour, while I had only a small Volkswagen. But now, I don't care. You do not stress about those little things anymore. Other things are much more important.* (HM)

> *So I was very focused on achievements and results. But in the course of years I learned to become more process-oriented. […] In the past, I always wanted to know: I am working on this and that means I will be over there in the end. And now it is important that what I do right now is fun. The results in the end are less important.* (AD)

3.8 Steps towards social reintegration

Another part of the recovery process is social recovery, or social reintegration. When a certain stabilisation is established and reorientation has led to ideas about desired quality of life, people develop certain goals with regard to desired life situations. However, this process is not as straightforward as it appears. Many people in the narratives also used reorientation to set steps for reintegration. But these steps were often meant to *explore possibilities*, both personal possibilities with regard to maintaining stability and social possibilities. In this respect, reorientation is often intertwined with reintegration. In addition, people use a domain in which 'normal living' is restored to reorientate en reintegrate into other domains (the phenomenon of 'mountain climbing', as described by Strauss *et al*., 1985). For instance, a stable home situation forms a basis from which to work on reintegration in the domain of working.

Learning by experience

Increasing social participation seems to be a way of developing more self-confidence. It is a means in the process of strengthening the identity. It helps with the development of social competences.

People 'learn by experience'. The basic sense of self is enforced by daily experiences. These might also include dealing with disappointments and setbacks. There is constant interaction between taking care of the personal niche and entering social domains.

Many people develop self-confidence in social relations by using the safe environments of mental health facilities, where fellow clients have a peer-support function (see the concept of the social niche in paragraph 3.9). The development of social competences is enhanced by social rewards such as affirmation and friendly relationships.

In the narratives it can be seen how each individual walked his or her own path, setting steps towards social participation. Social reintegration might take place in the different domains of life, such as home life, work, education, leisure and family relationships. For social reintegration, adaptation and coping competences are as important as in the stabilisation and reorientation phases. Now, these competences refer to adapting to external environments, as would be the case in schools and work places, for example. Social competences are needed to shift the social status. Often a transition point is marked by a

shift of social status. There are basically two types of social role shifts. The first is if a person retakes old roles. The other if a person becomes engaged in new roles.

People search for meaningful activities. My study confirms a phenomenological study by Godschalx (1987), who concluded that an activity is considered meaningful if it offered either a sense of accomplishment or a sense of usefulness. The participants in my study found this meaning in many different activities. These activities are listed in the Table 3.4.

Table 3.4: Meaningful activities in different life domains

Life domain	*Activities*
Domain of the household	Doing household chores, preparing meals, baking bread, taking care of children, taking care of a pet
Domain of learning	Following a social education, getting a college degree, doing an art course to become an artist
Domain of work	Working as a gardener, nursing aid, bicycle mechanic, trainer, housekeeper or recovery group leader, setting up a business, working in a canteen, doing administration
Domain of leisure	Playing chess, painting, playing the piano, jogging, swimming, supporting a soccer club, joining a Tai Chi group, walking the dog
Domain of social relations	Being a son, a friend, a partner
Domain of religion and spirituality	Joining a church community, practising meditation
Domain of (mental) health	Being a participant of a day activity or rehabilitation centre, becoming the chairman of a consumer council, joining a multilogue group, educating health care professionals on how to treat clients the right way

A sense of accomplishment or usefulness refers to existential needs. In the framework of recovery, activities or social roles as mentioned above play a strong *affirmative* role. People urgently seek affirmation of the healthy part of their personhood, of being capable of achievements. They want affirmation of their very being (*cf*. Honneth, 1985; Terruwe, 1978). By engaging in activities and/or social roles, *status* is obtained. The word status has a specific meaning here. It is not the status expressed in terms of being rich or having a 'high position' in society. It is the status derived from personally meaningful activities and roles.

The process of social reintegration reinforces both identity and autonomy. People discover their talents and passions. By using their strengths they also increase their sense of autonomy.[21]

[21] The relationship between the notions of identity, vulnerability and autonomy, and care will be discussed in Chapter 5.

Coping with stigmatisation

A phenomenon that was encountered in this study, and which has been described in the literature since the times of Goffman's famous *Asylums* (1961), is stigmatisation. In most of the narratives, stigmatisation was not mentioned explicitly; however, many of the aspects that were described are related to the issue of stigmatisation.

Box 3.3 Stigmatisation

Having a psychiatric illness or being 'a psychiatric patient' is strongly associated with stigmatisation. In the literature, a distinction is made between enacted stigma, perceived stigma, public stigma and self-stigma (De Goei, Plooy & Van Weeghel, 2005). *Enacted* stigma relates to an open form of discrimination. *Perceived* stigma entails the feeling of being stigmatised. *Public* stigma is associated with the ideas of a society. *Self*-stigma occurs when the person stigmatises him- or herself as being a psychiatric patient (Van 't Veer, 2008).

Admittance to a psychiatric hospital gives the person a label of being mad, dangerous and incompetent. Psychiatric conditions are regarded with fear and rejecting attitudes by the general public. In this respect, psychiatric illness differs from most other diseases. Link, Cullen, Frank and Wozniak (1989) and Link and Phelan (2001) state that harmful effects of stigmatisation occur because in our society negative images about people with psychiatric conditions are internalised since childhood. When someone becomes a psychiatric patient, knowledge about the attitude of others becomes personally applicable. Now, suddenly, you are on the other side. You belong to the category that is subject to denial and exclusion.

Plooy (2006) describes this as follows:

> "When I, halfway through the 1980s, was admitted to the psychiatric hospital of W., my life changed for good. Three things were happening to me: I met anxiety, depression and psychosis; I met the strange world and laws of psychiatry, and most of all: from that moment on I belonged to the others."

Within the range of psychiatric disorders, other citizens experience even a greater social distance from people with the diagnosis of schizophrenia than from people with other psychiatric diagnoses (Penn, Kohlmaier & Corrigan, 2000). Also from the side of their family, people with a psychiatric disorder often experience misunderstanding and ignorance (Thornicroft, 2006).

Stigmatisation affects people with severe mental illnesses in all aspects of their lives. Social relations change and admission to the housing or labour market becomes more difficult (Corrigan, 2005; Mezzina *et al*., 2006a).

In a recovery process, people with psychiatric experiences do not only have to handle the vulnerability caused by the illness, but also the vulnerability caused by stigmatisation. While reviewing their experiences, people have to deal psychologically with the stigma associated with the fact that they have a psychiatric diagnosis, and that they are or have been using

psychiatric services. They must decide on strategies to approach society when (re)entering social roles. Van Weeghel (2006) states that people with mental disabilities have to build their existence and self-image in society in "a triangle of full rejection, hidden presence and conditional acceptance".

Different means are used to handle stigmatisation, both on an individual and on a collective level (Van Weeghel, 2005). In the group of participants of this study, a clear distinction could be made between participants employing avoiding and opening ways to deal with stigmatisation. A number of participants in the study indicated that they isolated the 'psychiatric part' of their life as much as possible from other parts. They dealt with the stigma in different personal ways with the aid of a small circle of friends and mental health professionals. With regard to the 'outside world', they try to keep away from the burden of stigmatisation by avoiding speaking about their background, or by avoiding environments where they could be confronted with it. Part of this strategy is that these people do not want to be associated with consumer/client organisations or the recovery movement, because they consider this as a confirmation of the status or role they want to get rid of.

Another group of participants in my study used 'opening' or self-disclosing ways to overcome the stigma by sharing experiences with peers and by joining consumer initiatives. For them, self-help groups or the recovery movement are important vehicles for empowerment as a means to resist and fight stigmatisation.

Examples of stigmatisation

A participant explained the pain she suffered by having to be part of the psychiatric system.

> *I think what hurt me most is the gigantic stigma that is attached to the moment you end up in psychiatry. I was always at the other side [being a professional care worker herself JPW], and I had felt how thin the line was, all along. But god damned, then you are inside! And then you look outside, and you see that life continues, and I really had the feeling: It is all over.* (EH)

Mental health professionals themselves often contribute to stigmatisation, for example by paternalistic behaviour or by confirming negative stereotypes, such as confirming the viewpoint that someone is dangerous or unreliable.

> *I wanted to go a general hospital, but they brought me here. It was horrible,also for my husband and my children. […] I was put in an isolation room and could not get out. No-one talked to me. It was so humiliating.* (BE)

> *There are old-fashioned doctors who have this authoritarian style. Once I had a psychiatrist who asked my social psychiatric nurse how I was. She thought that it still worked that way, that patients are not capable of explaining things themselves. Yes, then you really make mistakes.* (NS)

The negative label associated with psychiatric conditions is often internalised. Internalisation or *self-stigmatisation* may lead to the adoption of a patient role, a negative self-image and low self-esteem (Leff, 2006).

> *I had the feeling, for instance when I started as a trainer, that I had a stamp on my forehead. Nobody sees it, but I still had that feeling. So, for sure the environment can give a stigma, but*

actually I am the one with the largest stigma. And I have to work on this myself, together with others. (EH)

People use both avoiding and opening ways to deal with stigmatisation. KP avoided public stigma by not talking about his psychiatric past and finding a regular job.

Yes, I am glad that I have not joined H [social work project JPW]. It would not have been suitable for me. I mean, it is nice that it exists, but to spud out weeds in public gardens all day with people who have something, which can be seen, sometimes. Nothing to the discredit of those people, but for me it would not have been good. And now I am in a regular company, and you are just normally accepted.

My work pleases me a lot, there are nice people. […] They don't know what it is, don't understand a bit, don't want to know. But they take me as I am. (KP)

EH was actively involved in public anti-stigma campaigns. She was involved in the organisation of cultural festivals where music, theatre and films were used to create a more positive image. She compared the process of getting rid of self-stigmatisation with the emancipation and gay movements:

It resembles the gay movement. You have to get out of the closet.

NS was asked to tell about his daily life with schizophrenia by making an exhibition with texts and pictures. This offered him a means of 'coming out'.

After being in my house for so long, I was ready to go out again. But how do I dare to look them in the face? […] Now I am not ashamed anymore. I even had an exhibition in the library. It was about the daily life of a schizophrenia patient. I am quite proud that they asked me, and I was also afraid. Because it was going to be exhibited in the library, with large posters, and all the pictures you see there. But I got a lot of positive reactions. (NS)

Plooy (2006) states the following:

> Psychiatric clients are the strongest factor in fighting stigma. By making them selves known and by telling their story. This observation has consequences. It means that clients have to be supported in their empowerment and recovery. Before you have the courage to expose yourself you have to get rid of your self-stigmatisation. You have to appreciate yourself and to produce the audacity to step outside and to withstand the societal stigma. Recovery is the answer to self-stigmatisation. And it gives the power to fight for social inclusion.

3.9 Environmental resources and social niches

Environmental resources

The participants in this study were or had been using different types of environments which were relevant for their recovery. I found three types of environments in the narratives: natural environments, peer environments and mental health environments. However, in many narratives, participants also talked about environments that caused stress and were damaging. It also became clear that the relationship between the personal niche and social environments is often an ambiguous one.[22] On the one hand, people need social relations for a number of reasons, while on the other hand, these interactions cause stress and may be potentially risky. I now focus on environments that are positive resources for coping with the vulnerability and for recovery.

Facilitating environments serve as resources for basic needs such as housing and socialising. They provide opportunities for activities and social roles. They serve as places for reorientation, affirmation and development.

An important feature of environmental resources in general is that in order to contribute to recovery they should be *supportive* to the person using the environment (Taylor, 1997). In terms of the international classification of human functioning (WHO, 2001), we might speak about resources needed for (recovering and maintaining) health, both on the physiological and psychological level and on the level of activities and participation. In terms of addressing the needs defined by Maslow, support can be categorised into the level of physiological needs, security needs, love and belonging needs, esteem needs, experiential needs and self-actualisation needs.

A physical personalised space, such as an apartment or a room, is an important 'home base' for securing safety within the personal niche. The way in which people organise and decorate this space has to correspond with their own ideas of self-containment (*cf*. Warner, 2000*)*. Personal belongings, but also pets, can be part of these physical arrangements.

As in other studies discussed in Chapter 2, the importance of having decent housing, enough financial means and the value of the social security system also came to the fore in this study.

For a number of people, the number of environments they actively and frequently use is rather limited. There seems to be a relationship between the degree of vulnerability, age and the number of environments that are used. The higher the vulnerability, the fewer different environments are used. The younger participants in the study used more different environments, and were also more active with regard to social participation. Future research should prove whether this is a significant finding. A hypothesis might be that as long as the emphasis is on stabilisation, on maintaining the balance within the boundaries of the personal niche, engagement in too many environments is too difficult to handle. Younger

[22] This is also illustrated in a study of Van Doorn (2010) about perceptions of time and space of homeless people. In the absence of a private space homeless people have much difficulty creating and maintaining a personal niche. In the public sphere there are often a lot of threats to deal with and insufficient resources to feel safe.

people seek more actively for change and progress. They also lack a history of hospitalisation and in general do not suffer from the effect of social exclusion and segregation from natural social networks. This might explain why it is easier for them to make use of different environments and facilities.

The *ecological structure* of an environment consists of physical, social and psychological elements. In the participants' stories it is remarkable that they talked mostly about the social and psychological factors that had meaning for them. Socially they spoke about the importance of belonging to a community of people and of being found at a specific place (such as a day centre, a work place, a building where a meeting of a multilogue group is held). Sometimes there was a personal relationship, sometimes there was only a connection by the mere fact that other people are participating in the same environment. Simply the feeling of being connected in one way or another, even if it is only through membership of a certain community, gives a sense of belonging, which is important in the process of social reintegration.

In my study, the participants tried to connect to the world in a 'safe way'. One way to do this is to use strategies of "positive withdrawal", which entails the "negotiation of distance from the social milieu" (Corin & Lauzon, 1994, p. 271). This means that people look for relations and roles that enable them to participate, but at the same time are not threatening to their personal niche. This can be regarded as conditions of social environments that enable people to 'recover socially', or to simply be able to fulfil meaningful activities and social roles. The expansion of a personal position within the world refers to discovering ways in which one can engage in a broader social context. When coping with the disability, the challenge is one of identifying those avenues to reengagement in the world that remain open and available, and accessing these avenues in ways that foster, rather than threaten, a positive sense of self (Sells *et al*., 2006).

Box 3.4 Positive withdrawal

Corin and Lauzon (1992; 1994) introduced the notion of 'positive withdrawal'. In their study, in which the use of public locations by people in recovery from schizophrenia was investigated, people with the diagnosis of schizophrenia who managed to avoid rehospitalisation better than others had in common a stance that distanced them from and yet simultaneously fostered participation across various social spheres.

It seems that people with a psychiatric disability like to use spaces in which people typically come and go within a narrow timeframe, and with only superficial social contact. It could be viewed as an attempt to move towards others within a context that feels safe yet meaningful. In more or less impersonal spaces, one can be in the company of others without the social demands of intimate interaction. The same phenomenon occurs when people participate in activities that can be performed without getting too involved personally or emotionally, such as painting, writing poetry or attending church. One of the common functions of positive withdrawal that was found in my study is that it helps to maintain a vital personal niche through which the person can approach the world.

Social niches

Managing a personal niche often means that social participation has some limitations, for example in terms of productivity, locus of control or personal involvement. From my study it appears that most of the participants used social environments that are adapted to or are not intervening with the requirements of their personal niche. I call these environments *social niches*. Most of these niches were created by mental health agencies; however, 'peer environments' also serve as social niches. I noticed, however, a difference between the more vulnerable people, whose 'personal niche' comprised a great sensitivity to stress factors, and the less vulnerable people, whose personal niche was much easier to manage.[23] In the latter category, social relationships were less complicated to handle and their social network was much larger. The former group used more facilities offered by mental health agencies, while the latter group used more consumer-run initiatives.

Box 3.5 Peer environments

Working in a consumer-driven centre has many advantages. It offers a job opportunity and provides status within the user movement. It provides strong peer support, and it is a working environment that is strongly adapted to requirements of the personal space. At the same time, the participants in my study who worked in such a centre indicated that they themselves were still in a recovery process, and that their work is an important resource for them. This confirms findings from studies on the potentially powerful role of peer support for recovery (Davidson, Chinman, Sells & Rowe, 2006; Davidson *et al*., 1999; Solomon, 2004). Among other contributions, peer support offers a sense of belonging and positive feedback of a person's own self-worth.

Other participants participated in multilogue groups, which provided them with considerable support in their recovery process (for the concept of multilogue see Mölders, 2003; 2004).

In the intersubjective field of a social niche, the personal limitations (or in other words the necessary conditions for social participation) are acknowledged, providing room for meaningful social functioning. An optimal situation seems to be one in which on the one hand the personal niche is respected and on the other hand valued social participation is realised on the basis of interests, talents and skills.

The proof of the pudding is that a successful match is made between the personal niche and the social niche.

A great example of this match is found in EH's narrative:
I didn't want stress and too much responsibility and things like that. I ran into a person who was starting to organise bicycle lessons for foreign women. She was very passionate, and if I like something I am also a passionate person. So both of us were crazy about cycling. So we started this together, and it went very well. […] I've been doing this for 13

[23] This is no strict but a relative distinction. A number of participants in the study had moved over the course of time to a less vulnerable condition.

years now. […] What was great was that she saw my qualities. And that she made me use them, because I was so scared that I actually did not dare to do anything. (EH)

EH needed a social niche that had to meet a number of personal criteria: it had to be relatively stress-free, it had to be safe, and not too many responsibilities should be placed on her. At the same time, the activities had to be useful. The person featuring in this quotation provided a powerful support function, both in terms of acknowledgement and affirmation, but also in terms of collaboration by offering her the role of a partner in the project. She also created together with her an environment in which concrete steps could be set (see the next paragraph). For EH, this was very empowering: Her strengths were noticed and she had the opportunity to use and develop them, thereby gaining self-confidence and playing a valuable role again.

Rapp and Gosha (2006, p. 167) would consider as what they call "a perfect niche", a place that is perfectly tuned into the possibilities and needs of the person without having to (be) change(d).

Social niches in mental health care

Social niches as created by mental health and social care agencies often provide safety, options for 'positive withdrawal' and opportunities for appreciated activities, peer support and affirmation. In this respect, they are, to use the words of Rapp and Goscha (2006), *enabling niches*.[24]

Psychosocial rehabilitation centres seem to function as safe havens where a good match can be made between the personal niche and a social environment. Wards of psychiatric hospitals also serve as safe havens, offering considerable protection. However, people experience these places more as environments needed in times of destabilisation than as resources for reintegration.

Some participants indicated that the use of day centres or vocational rehabilitation projects is temporary, for others the length of use was indistinct. Some went there on a daily basis; some once, twice or three times a week. They used these resources for different purposes, such as the following:

* As a part of their daily structure (maintaining the personal niche)
* For diversion (a way of avoiding too much self-focusing)
* For socialising
* To develop competences
* To receive support services

In these environments, people can use and develop social role skills with regard to social relationships, recreational activities and work. Most of the participants in the study that used these social niches indicated that they had some desire to move away from these special environments, but that they were at the same time reluctant to do so, because these environments provided the right conditions for them to maintain their personal space. Moving on to ordinary environments in the community is considered a considerable risk.

AD had found himself an adequate social niche in a rehabilitation centre. In his story, a number of qualities connected to the niche were demonstrated:

[24] However, Rapp and Goscha consider mental health facilities as an environment of last choice, because these facilities do not foster community integration. At the same time, one could state that rehabilitation centres offer a type of social niche, which is enabling for people in terms of being adapted to their personal niche and as a way to engage in meaningful ways of social participation.

I took the step to go to the day activity centre. Well, I felt a little part of a kind of social community. That feeling was very important to me.

Nowadays I also dare to say: "No, this task is too heavy for me; I cannot do it". And in that sense, B [the rehabilitation day centre JPW] helps me, because it is easier to tell here than in business, because here are more people with vulnerabilities.

By the end of 2003 I started preparing meals here at B, together with a pall, for a large group of people, usually around 15 people. I started to be on firmer grounds. I liked to choose recipes, and sometimes it was exciting, because were they going to like it? But at a certain moment you discover that you got the hang of it. So I really felt: I am doing something useful, I am doing something of public use. And it was really good to do it together with F. [a peer at the centre JPW]. (AD)

At the time of the interviews, PV had been using the artist studio in the rehabilitation centre for two years. For him it was a place where he started to get some firm ground again. It had the function of reconstructing his identity and helping him to regain his self-confidence. And it helped him to construct his personal niche.

I needed to develop some kind of firmness. S [rehabilitation centre JPW] offered me the possibility to practice, to grow, and also to do other things then just painting. […] Making art is more than a hobby. […] The centre has played a big role for me. I found a new direction in which I feel at home. […] We help each other; we teach each other things. So the atmosphere is good. […] I withhold from getting too personally involved […]. Only one woman is becoming a friend. […] I think it is all a bit too unsecure, too unstable for me. Other people, their moods. After all, they are all people from psychiatry. And given my own, well weaknesses, I would not say, vulnerabilities, I am a bit careful. (PV)

RL was also positive about what the rehabilitation centre meant to him.

You have to function well and part of it is a certain structure, a programme. M [rehabilitation centre where people can meet and take part in activities JPW] is a part of it. And yes, that's fun. I go there on my bike, I have a hot meal in the afternoon, I do some volunteer work. There I can work independently, and if I have a question I talk about it. Then I bike back. Yes, I like to go there. It is a good place, a support. (RL)

3.10 Social support

One of the features of social niches is that it contains a *social network* that can be used as a resource for socialisation and for affirmation, two important functions of social support.[25] Social support can be offered by an individual or in the context of a particular environment, for example a working environment or the environment of a mental health setting. Besides the social niches provided by mental health and social agencies, the networks of family, friends and peer support or recovery groups provide important support systems. My study confirms the findings of other studies such as that of Denhov (2003) and Topor *et al*. (2006), which emphasise that the continuity of the presence of family members and long-time friends is a huge support. By means of these people's presence, they represent a continuity that extends back to the person's pre-illness history. They demonstrate that the person cannot be reduced to the stigmatised image of someone whose whole make-up consists only of symptoms and shortcomings. In addition, they are the bearers of hope for a future that differs from a present life marked by suffering and limitations. Standing alongside the person means that he or she can rely on the family member or friend's strengths and knowledge when times are difficult; in other words, the person is not alone in the world.

Social support is essential in a recovery process. The different types of support as described in the literature (emotional, instrumental, appraisal and informational support) came to the fore from the narratives. Support is necessary in all phases of the process. Sometimes support is appreciated instantaneously, sometimes in retrospective. Often a combination of different types of support is given. Support is only support if it is *perceived* as supportive. This perception seems to depend on different factors.

Social support has a temporal dimension. Some types of support are incidental, but can have a great impact. Others are valuable by the virtue of durability or permanency. Sometimes this durability lasts throughout one particular important period, such as the whole period of stabilisation or reorientation. This is mostly the case with support by mental health professionals. Other supportive relationships last throughout a large period of life. This is mostly the case with support by close family members. Many of the participants in my study had had long-lasting relationships with professionals. If a relationship is long-lasting, this often takes the form of companionship and watchmanship. I elaborate on these findings in the next chapter.

Some people perceive a certain form of support as valuable in retrospective. Many participants disliked the role of family members or friends at the time they were in crisis and only accepted professional help because they were pushed, but afterwards they were mostly grateful for these actions. Apparently, an important condition is that these invasive types of actions are embedded in a long-term caring relationship.

[25] Berkman, Glass, Brissette and Seeman (2000) have studied the relationship between social networks and health. They argue that networks operate at the behavioural level through four primary pathways: (1) the provision of social support; (2) social influence; (3) social engagement and attachment; and (4) access to resources and material goods. These micro-psychosocial and behavioural processes then influence even more proximate pathways to health status, including direct physiological stress responses and psychological states and traits such as self-esteem, self-efficacy and security.

Box 3.6 Types of social support

Social support can be defined as the "availability of people on whom we can rely: people who let us know that they care about, value, and love us" and are willing to assist us to meet our resource and psychosocial needs (Sarason, Levine, Basham & Sarason, 1983, p. 127). Research has demonstrated that these supportive relationships help to contribute to positive adjustment and to buffer against stressors and adversities, including medical and psychiatric problems (e.g. Ell, 1996; George, Blazer, Hughes & Folwer, 1989; Gottlieb, 1981; Walsh & Connelly, 1996).

Social support is typically divided into subtypes, which include emotional, instrumental, appraisal and informational support (Weiss, 1974). *Emotional support* is related to the amount of "love and caring, sympathy and understanding and/or esteem or value available from others" (Thoits, 1995, p. 55). Emotional support is most often provided by a confidant or intimate other, although less intimate ties can provide such support as well. *Instrumental support* refers to help, aid or assistance with tangible needs such as buying groceries, getting to appointments, phoning, cooking and paying bills. House (1981) refers to instrumental support as aid in kind, money or labour. *Appraisal support* relates to help with decision making, giving appropriate feedback, or helping to decide which course of action to take. *Informational support* is related to the provision of advice, guidance and feedback or information in the service of particular needs. Emotional, appraisal and informational support are often difficult to disaggregate and have various other connotations (e.g. self-esteem support). Schrameijer (1990) has extensively studied the concept of social support. He states that support is a context-specific process; that is, its meaning is derived from specific situations, needs and relationships. Support becomes supportive if it is not only available or provided, but also perceived and used. This is a complicated area. Support from others can only be perceived as valuable if there is sensitivity and receptivity. Support is an interactive concept.

Elaborating on this dynamic approach, my study indicates that the context of social support consists of situational, (inter)personal and temporal dimensions.

It can therefore be concluded that there are two categories of support. One is *temporary support with a high impact*. This type of support addresses an urgent need, for example the need to be comforted, to be heard or to solve a pressing problem. The other category is *long-lasting support*. The data analysis revealed that there are indications that continuity of people around the person is an important factor. Continuity is expressed by people not breaking the relationship and staying in touch. In many cases family members fulfil this role; however, professionals with a long-term relationship are also considered highly supportive. The mere presence of people in both bad and better times seems to be an important support factor. At a psychological level, these relationships provide recognition, acknowledgment and thereby hope. They provide a connection to the world.

The quality of support also involves a distance that is experienced by the person as being comfortable, in other words not too close and not too far away. In studies of psychological health, one consistent finding is that the perceived adequacy of social support, more so than the availability of support, appears to be most important (Berkman *et al*., 2000; Henderson,

1981). This is evident from a number of recovery studies, including my study. There may be many resources available, but only if they are perceived as adequate to the personal needs a match between need and resource is made. An additional conclusion from my study is that continuity in availability is also considered 'adequate'. It is important, however, to decide what is considered 'adequate' by the person concerned.

Natural support

Relatives were important resources for the younger participants in my study. Parents play important roles, both in times of crisis and during the process of recovery. They provided different types of social support, as is illustrated by the following examples.

> *And I can always make an appeal to my parents. They live [...] five kilometres from here. I keep in touch with them. I can always have dinner there. On Saturday or Sunday.* (RL)

When NS discontinued his studies because he got ill, he moved to the village where his parents lived after his second hospitalisation.

> *My parents are a factor why I am doing very well right now. I just went on holidays for a week with them. That was very nice.* (NS)

At a time when NS was very depressed and wished he could die, he decided he wanted to keep on living because *I could not hurt my parents.* His parents also fulfilled other functions: They gave him literature on schizophrenia and advised him to go to a haptonomist as a way to help him to better acknowledge his feelings. They urged mental health workers to continue to visit him at home, even though he rejected them because he thought he did not need them.

In the course of reorientation, AD discovered a book in which he recognised much of his own history and experiences. It helped him a lot to put things into perspective.

> *It was very emotional but also a relief to me. I talked about it with my parents, and they read it as well. They understood everything, so that was very pleasant*.
> We see here an act of affirmation (see Chapter 4).

AD told about the close involvement of his parents, sister and brother:

> *I saw an enormous concern when things went wrong with me. The relationship with my parents is improving all the time, but I can't say that they actively contributed to my recovery. But they have not obstructed it either. Their concern touched me.* (AD)

His friends also played an important role:

> *The friends, who really know my story, date back from my time at university. That has been very good for me, that almost no one has let me down. Some people think it is utterly scary, to be admitted, and psychiatry and all that. Only one nephew has withdrawn. The rest, all my friends, have only become closer. […] They all came to visit me when I was hospitalised. They were all concerned. No, in fact, this has strengthened our relationships.* (AD)

Family members and friends can intervene as advocates on the person's behalf, especially in times when the person is not able to stand up for him- or herself. This is illustrated in the dramatic example of GK, at a time when he was placed in an isolation room for three weeks.

My father and mother had phoned and said to the social worker: "Please get him out. It does not help at all. He is only getting worse". (GK)

AD told the following: *In the beginning I blamed my brother and sister that they had phoned to get me admitted. They kept on pushing until I agreed. But after all it has been very good that I had been hospitalised. My brother was very caring, and that was doing me well. From my brother I got a lot of support.* (AD)

For SW, his sister played an important role for as long as 30 years. After his last manic episode, which happened when he was travelling in Indonesia, he became depressive, not able to move. His sister undertook the long journey to take him home. He realised that he had caused a lot of trouble over the years for both his sister and brother.

You know, with this disorder, it is the well-known story of a person leaving a lot of shit behind. (SW)

His sister did not end her involvement there. She continued to support him. When he became homeless, she found him a shelter. She also played an active role in his early warning-sign plan. She knew his vulnerability very well. At times when he was unable to pull back from the borders of the safety zone in his personal space and she became alarmed by certain signals, she was permitted to contact his psychiatrist. He had also given permission to the workers at the homeless shelter where he stayed to contact his sister or his psychiatrist for consultation.

I have granted her permission, and this is pretty difficult for me, if they notice anything to consult K. [psychiatrist JPW] behind my back. They have to tell me later, but they are allowed to do this without warning me first. That's in the plan. It is very difficult for me, because I hate it when people do things behind my back, but it is a good safety net. (SW)

From research on social networks it is known that it is not always the physical distance or the contact frequency that matters most, but the degree of perceived connectedness.
In the story of RL, an uncle features, with whom he had hardly had any real contact. When he became psychotic, he decided to go to him.

At a certain moment I went to H. [a city in Holland JPW] by public transport. Because an uncle of mine lives there. That uncle had a vegetable garden. And I had a good bond with this uncle. He had something ... I don't know precisely how ... I thought this uncle could mean something to me. And not so much because of my psychotic ideas, but that it would do me well to go to my uncle. Because I had a good relationship with him. (RL)

Distance and closeness are interrelated. People can be at a physical distance but still be perceived as relationally close by.

Pets

A specific type of support comes from pets, specifically cats and dogs. This was also reported in other qualitative studies (Boevink *et al*., 2002; Topor, 2001). Three participants in my study specifically mentioned the importance of their pet to them.

My dog, yes, he has been very important. Because of the dog I stepped outside. You make social contact with other people with a dog. Without knowing, you start to chat. You do not feel alone. If you come home he wags his tail at the door. And I am already going out with him at 6 in the morning. Because I cannot sleep [...], so I take a walk with the dog. But if you are alone, you are not going to walk a turn at 6 in the morning; because everybody would say you're mad. But with a dog they say: "Oh, he is walking his dog already pretty early!" I owe a lot to this, that I got the dog from the asylum. The last

three, four years, he has really pulled me through.
Sometimes I don't feel like doing anything. But then he comes and sits in front of me, with his wondering head. And then I go. And once I am outside, I think, Life it is not really that bad. (HM)

HM's dog represented a number of values for him. It provided him with company and acted as an antidote to loneliness. It was a means of having social contact with others in the neighbourhood. It gave him the social status of a dog owner, and enabled him to meet with other dog owners. Instead of being labelled as a fool, a tramp wandering around the streets at 6 o'clock in the morning, it provided him with a means to behave in a socially accepted way, and at the same time to deal with his sleeping problem. Finally, the dog meant a lot for his health. Whenever he became passive (which in his case was a sign of possible upcoming depression), the dog invited him to become active again. His words *he has really pulled me through* are very interesting. The dog literally pulled at his leash, but also metaphorically pulled him through difficult periods.

PV's pet provided him with company, but also with a meaningful goal: coming home for someone, and a responsibility: taking care of a living creature.

When I started to feel better, I got a cat from the asylum. Suddenly I had someone to care for, and to come home for. And that was very nice. A cat gives a good atmosphere in the house, good energy. […] It is cosy when he is around. And at night, when I am watching television or if I am sitting at the table like this, he comes to sit cosily beside me, to get a little attention. This make me feel quite well. (PV)

3.11 Resources for empowerment

One of the conclusions from the review in Chapter 2 is that empowerment is central in the process of recovery. I therefore analysed the factors that potentially contribute to empowerment that emerged from the data in this study.

As far as motivation to set a step or to make a change is concerned, both extrinsic and intrinsic factors can be determined. Extrinsic motivational factors may lead to increasing intrinsic motivation. From my analysis it seems that relevant individual factors are a certain goal orientation, enough self-confidence, enough physical and mental energy, and the belief someone has in his or her own possibilities. These can all be considered inner strengths. Positive (real-time) experiences, for example the experience that a task or job is performed successfully, contribute to empowerment. Success comprises both personal satisfaction (contributing to a sense of wellbeing and happiness) and the appreciation of others (contributing to validation and valuation). All these factors also contribute to the development of a new sense of self as an integrated entity or, in other words, to the (re)constitution of the personal identity.

Relevant external factors that seem to be important sources to be able to move forward are others who provide support, hope, encouragement and opportunities to change living conditions, including material resources such as housing and financial means.

A specific factor is *acknowledgement*. This entails the recognition that you are (still) a human being, an individual with a personal identity. An element of this recognition is the

acknowledgement of personal qualities such as talents, skills and performances. Associated with this is the (growing) belief that life is meaningful, and that there is a future perspective. I will elaborate on the notion of recognition in chapters 4 and 5.

The phases of a recovery process can be considered a developmental process and a process of continuous empowerment. A developmental process is characterised by learning and growing. All the participants in this study showed learning capacities, even in cases of severe vulnerability. A strong motivation for learning comes from the drive to improve the personal situation, both the physical/mental situation and the social situation. Learning opportunities are sometimes created by people themselves and sometimes by others. Psychotherapy and social niches were used by many participants in this study to learn about themselves, to learn from past experiences, and to learn how to take care of vulnerability.

Reintegration on a psychological level is attained through achievements with regard to stabilisation and reorientation. When a basic level of vulnerability management and identity (re)construction has been accomplished, the emphasis shifts more towards social reintegration. A strong motivator is a desire or goal to acquire a specific situation, for example a housing situation, education, or a job. Having acquired this situation enables the person to use and develop his or her talents, and to participate in social networks. Here valuable social roles and citizenship are recognised as important affirmative and supportive factors that increase the level of empowerment.

Empowering factors

Different categories of empowering factors came to the fore in this study. In the beginning of the recovery process already surviving a crisis situation and feeling better can be regarded as empowering factors.

Feeling better

Establishing a *basic physical level of wellbeing* often provides a basis for strengthening psychological strengths. For all the participants in my study, medication was or had been an important external resource.

In the example of BE, medication had enabled her to use her mental capacities. Immediately after having returned to a basic level of reasoning, she started to use a self-motivational strategy.

> *That medication made me think somewhat more realistic. So I thought: I have to put my shoulder to it, because otherwise I will never come out of this misery.* (BE)

An important source in the stabilisation phase is when people start to feel better. When, for example, a type of medication results in less tension, less anxiety or a relief of depression, hope is instilled that the worst is over. It seems important that hope can be maintained.

> *The antidepressants worked very well. […] After a while I felt reborn again.* (AD)

Urge to survive

Internal motivators are strong contributors to recovery. A primary drive for recovery is what AD simply put as *an enormous urge to survive* and *the wish to have a better life*.

> *Yes, in the beginning it was a combination of a tremendous urge to survive, and the wish to have a better life. This pushed me forward enormously. There had been a time that I only had to survive.* (AD)

What gives the strength to make changes? In a crisis situation, when there is a lot of pressure, people feel so entrapped or 'pushed to the edge' that this gives a strong impulse to

'fight back'. Sometimes unexpected forces come to the surface. The current hopeless situation is resisted. A strong *resilience* manifested in a number of stories.

> *Then they wanted me to put in X.* [a long-stay ward JPW]*. That's for chronic patients. There I could live for a number of years. Yes, and this I didn't want at all. Then I attempted suicide.* (KP)

Resistance is triggered through circumstances that are conceived to be a threat to the basic existence. Resilience is necessary to move into action. Another reaction might be to 'freeze'. In some stories, there were examples of 'freezing', where apparently there was no resistance. But even in those stories, at other moments there was a kind of opposition to the situation. In such cases, people then sometimes did not yet know what they wanted from their situation; they just knew that they did not want *this*.

> *I didn't want to stay there anymore. I was used to living alone. I kept on telling them: "You can't expect from me to get well in this environment. I am used to being by myself, now I sleep with three or four others in one room. It is on my mind all day, I get shit ill of this. How can I get better, if I am constantly irritated, because I am not used to this. I need a room for myself". And then I got a room for myself. And then I said: "Yes, Jesus, now I have to cook twice a week for people that I have not chosen". I always cooked for myself, I did everything for myself. How can I get better in this situation? And this went on like that. They said, "Boy you're negative". I said, "OK, but I am so fed up with this". Then they let me go.* (NS)

A specific source of motivation is the fact that the person had *managed to survive*. A special case is FJ, who miraculously survived a jump from a high building.

> *It has given me much strength, the fact that I survived.* (FJ)

Others had managed to survive nasty circumstances and experiences in a psychiatric hospital.

> *It was so awful, so miserable there. Without any rights. I thought: I* have *to get out of here.* (BE)

This experience gave her the motivation to fight herself out of the hospital. Another example comes from EH.

> *At a particular moment a nurse said to me: "We are going to put you in the isolation room". Well, in the isolation room I went furious. Furious, furious, furious. […] It was horrible that it went that way. […] But what is even more horrible, is that nobody talks to you, not at that moment, not afterwards. […] You are not being heard.* (EH)

This experience provided EH with the motivation to become, at a later stage, a member of an advocacy group that strived for better treatment, and to share her experiences with others.

There seems to be a difference between the sources of motivation which make people going into action from the 'bottom of the well' and those later on in the process.

Knowing what is wrong with one, for example by having a clear diagnosis made by a psychiatrist, gives something to hold on to, and empowers one to make a transition.

> *So finally I knew were to direct myself to, what my problem really was. Since then I have actually moved forward very fast.* (AD)

Goal orientation

Another category of motivation concerns having a *goal orientation*. In a crisis situation, the goal orientation is a very basic existential one: The goal is to survive or to stabilise. The emphasis is on the domains of health and self-

care, although activities in other domains, such as work or socialisation, are used for health purposes.

> *And then at a certain moment in November, I had the feeling that if I went on like that, I would be readmitted again. During my last admission I had good experiences with a day centre, X. So I was thinking, let me bike there and try to become active again. I have a headache, I feel bad, but I need to do something.* (AD)

Some participants were unable to develop a goal orientation, because the disease impaired them too much. Only after treatment and active support were they able to develop personal motivation.

> *At the ward I wanted to stay in my bed all the time. But it was not allowed and they pushed me to go to the day centre. There I chatted a little with others. Drinking a cup of coffee, smoking a cigarette. Apparently that was their intention. I met other people, instead of lying in my bed. But in the beginning I didn't understand this. I was really resistant in the beginning. On quite a few occasions, I was outside and thought: Come here, I will blow your head off. Then someone came, and I was neatly helped into my coat. […] And from one thing came another. I went there often to drink a coffee, chatting. I showered in time. I worked in the bicycle workshop, and I went looking for those things myself. And no one said that I had to. They only said that it was better for me. That I tried to develop. Undertaking things myself. […] I was thinking: Well it is worth it. And at first I wouldn't have done this. […] But because of the medication. And the contact with the psychiatrist, and my children. I said: "Ah, I did this and that". And then they said: "Well done, again another step!".* (HM)

If basic existential needs are secured, the goal orientation usually shifts towards reorientation. The end of the reorientation phase is marked by the setting of goals that refer to a living situation, work, education or leisure. These goals are connected to purpose, meaning and social relationships.

> *I started to find myself a job. Especially work that I find useful. And regardless of [whether] it had status or not, I wanted to be meaningful for myself, and nice.* (EH)

The goal orientation shifts from a focus on basic needs such as self-care to the fulfilment of higher needs in Maslow's hierarchy. *Articulating* a goal seems to mark a future perspective. Then a goal can become a clear motivational factor and a beacon when moving forwards.

> *Yes, it is important to set a goal. That you have something to work on. Maybe in the end you can't reach something you really want, but you can make progress with other points. […] For example, I wanted very much to live by myself, that was my goal, one of my goals. Well, it has not worked out, at least not yet. Then I think, Well, I am not so bad off here [supported group home JPW]. I am all right here. You also try to see the positive side.* (RL)

Other people as sources of hope

Not everyone is able to create intrinsic motivation. Some of the participants in this study depended on others to provide them with hope.

> *Until a social worker provided an opening. She proposed to the team to discharge me to an open house. An open ward, after being in a closed one for seven years!* (GK)

Hope and confidence are also generated by good examples of people who were in the same circumstances and managed to get out.

I had examples of people who said: "I also know someone who has been depressed for two years after a psychosis". Well, that was actually enough for me, when I heard this, I said to myself: OK, I have to grant myself time. It can take a long time. (NS)

But the contrary is also true. Examples of other people who remained in the hospital, in the same deplorable circumstances, apparently without change, provide reason that the own situation is at least better, and gives a stimulus to work even more towards further progress.

If I see the people sitting in S [psychiatric hospital JPW]. That's a pity. […] They are 20 years younger than me, and they accept that they are there for the rest of their lives. They are there with a big belly, lying on the bed, eating pizza, smoking cigarettes. When I was there I also had a big belly, now I walk my dog for 15 kilometres a day. I look carefully at what I eat; I have lost 20 kilos in the past 6 years. They have given up, not me! (HM)

Once an opening is provided, or people have someone or something to hold on to, the seed of hope can grow the belief that something might change for the better. Belief leads to steps in the recovery process.

Then I had two conversations a week, and sometimes more, and then it went very well. Then, suddenly I got perspective. (GK)

I live thanks to her, because I had a very suicidal period. […] *She dragged me through this.* (SW)

Provided opportunities

For GK, the opportunity to move from a clinical ward to a 'ward in a house' at the end of the hospital was an important step forward. By providing him with this opportunity, he felt that others were expressing faith in him. By this step he could get more control over his own life. And, after many years inside locked wards, it marked a transition towards the real world. These were hope-giving and empowering factors for him.

A social worker said: "Is facility P. [a rehabilitation department JPW] *not an idea for him?" Open house; never occurred before. I lived closed for seven years. So always: Can I get out? Can I get in, can I get out? […] "Yes", she said. [...] So, fine, I went to a house, and there I've grown very much.* (GK)

HM had led a difficult life inside the hospital for five years, when …

The social worker got the idea: actually there is no progress. Maybe, if we let him go home …. Maybe the privacy of his own home, and the trust we have, can lead to a breakthrough. (HM)

This action did not immediately lead to a breakthrough. Only after two months in his house did he start to show little changes. It had taken him two years of small steps to get as far as he was. The continuous support of mental health professionals, both at home and during day treatment at the hospital, and a change of medication, were indispensable to his recovery process.

Recognition and acknowledgement

Another important source of empowerment is recognition and acknowledgement. They are evident from the narratives in many different forms:

* Acknowledgement of being an individual, with an own voice and opinion

They asked me what I wanted myself, how I felt about my future. (KP)

* Recognition and affirmation of strengths, talents and skills

They asked me to give a presentation for a group of 15 people. They saw I made a good performance. (AD)

He gave me compliments, like: "It is great you have come all this way", and "You know how to make your home very cosy". (KP)

The person is acknowledged as someone who has a personal opinion, who has knowledge, capacities and abilities and is able to manage his or her life. In the act of recognition and acknowledgement, the notions of respect and strengthening are included. The notion of recognition is elaborated on in the next chapters.

3.12 Helpful practices

A specific aim of this study was to investigate how professionals (mental health workers and other types of professionals) contribute to recovery, and especially what is perceived as helpful. The professionals who featured in the stories can be classified roughly into three different groups: professionals who obstruct recovery, professionals who appear in the stories as 'neutral' (not making a specific or outspoken contribution but also not being hindering), and professionals who are considered by the participants as supporters of recovery.

The contributions which make professionals supportive are often expressed by the participants in a remarkably clear way. By analysing the narratives, we can learn about the characteristics of 'people that are really helpful' and about the strategies they use to support recovery in an effective way.

Unhelpful practices

From the stories we learn about professionals who were *not* helpful, who sometimes even 'increased suffering', as phrased by Baart (2001). These professionals and professional environments hinder recovery.

The following examples illustrate this point:

What didn't help me was the isolation cell […]. A period of four weeks, five weeks, is much too long. They should never do that to people. It destroys them. (GK)

I was in this admission ward. […] With all their good intentions, it's unsafe, it's not warm, it's very incongruent. You see people with different visions; you can sense who likes to work with colleagues and who doesn't. They were always talking about us, not with us. They were just sitting in that shack [office JPW]. (EH)

At a certain moment a nurse said to me: "It is not going well with you. We are going to the separation room". (EH)

There are old-fashioned doctors who have this authoritarian style. Once I had a psychiatrist who asked my social psychiatric nurse how I was. She thought that it still worked that way, that patients are not capable of explaining things themselves. Yes, then you really make mistakes. (NS)

I could not get along with the psychiatrist. He asked far too difficult questions. I just could not understand him. So if we had a conversation of half an hour, I just kept my mouth shut for half an hour. (HM)

KP describes his admission to the psychiatric ward of a general hospital as follows:
People were friendly but they thought I was just some aggressive young bloke who was flipping because of the booze. This nurse said: "You first have to learn to talk, instead of beating someone. They did not say how, they did not really understand my problem, because much more was going on. He said: "Just go home to your mother and then it will be all right". And then you go home and after a couple of weeks you are back because it is not going right. It could have saved me a lot of misery if I had been treated right from the beginning.
In the psychiatric hospital he was transferred from one ward to another a number of times. *It was very annoying because you had no steady place to be treated and to settle down.* (KP)

When BE was hospitalised, she really missed someone to talk to about her experiences.
I just was admitted to the closed ward and had a room. You were just there. Period. There were nurses but they did not make any effort to make contact. They were not talking to you. About nothing. Nobody took the trouble to have a conversation. (BE)
I was placed in an isolation room and could not get out. No-one was talking to me. It was so humiliating. (BE)
BE felt that she was treated like an object, not like a human being. Her needs for attention to her suffering, to keep in touch and to talk about her experiences were neglected.

Different categories of 'unhelpful' practices emerge from these quotes.

1. Forms of 'distancing' – alienating behaviour that puts people at a distance:
* The inhumane intervention of putting people in isolation rooms, thereby treating them like prisoners, which can be aggravated by not talking to the person. Such people are isolated, not only physically, but also relationally. They lose every form of connection to the world – and this in a situation in which the person has already lost his or her self-orientation
* A lack of communication or vertical types of communication, for example not talking with someone, but talking about him or her, and a paternalistic attitude
* The use of language that is difficult to understand and thereby impedes communication

2. Inadequate professional knowledge, for example insufficient assessment of the problems and needs and inadequate treatment or advice

3. System disadvantages:
(a) Physically: moving people from one mental health facility to another (this happened in four of the thirteen narratives in this study). Each time the person has to adapt to another environment, to other people, to other ways of treatment
(b) Psychologically: treating the person as an object; humiliating behaviour; degrading the person to just a patient in a care system – a number to be treated.

These findings coincide with the experiences of people in many other countries. As reported in Chapter 2, psychiatric hospitals are often regarded by clients as restricting and dehumanising places.

From my analysis it seems that most of the professionals who featured in the stories did not focus explicitly on recovery. At the time of the study, knowledge about recovery processes and recovery factors was not yet commonplace. Professionals supported a person not explicitly with a view to recovery, but often in a more personal way, and helped the person in the context of an actual situation. This may be a crisis situation, a hospitalisation, life in a sheltered home or activities at a day centre. It is mostly in retrospective that people

could place these contributions in the frame of their own development or recovery process.[26]

What these professionals apparently have is the ability to connect and to relate to a person in a way that is perceived as valuable. A connection is usually made on two levels: the level of a relationship, and the level of needs.

> *Those ordinary caregivers, they are professional. You get attention, but it is professional attention that you get. You can't compare it to your mother putting her arm around you. You can't expect this; that will not happen. But there are people, who are professionals, but they have something extra, they give a certain warmth. They are professional, but they give something of themselves … a bit of warmth […]. This is something I really appreciate. Yes, I appreciate it. You can write that in your book.* (RL)

Professionals are perceived as helpful when they succeed in making a connection on a relational level. These professionals have a way of relating to the person so that the person feels that he or she is *seen* and *understood.* Being seen and understood can relate to different things: the suffering, a particular problem, a need. An aspect of understanding is that there is consideration of the feelings and the emotions attached to the problem or hidden under the surface.

Feeling that one is seen and understood is already helpful, because one knows that there is at least one person one can share experiences with. It breaks through isolation and loneliness. On a social level, one has someone to lean on, and this gives some emotional relief.

An important distinction can be made between professionals who are present in the life of the person for a short period and professionals who are present for a longer time. The former category makes a more incidental contribution, while the latter category makes a more fundamental and process-oriented contribution. Care workers who make an incidental contribution provide, for instance, emotional support during tough moments or play a role in a transition phase. They can contribute to a turning point.

> *In the morning I was sitting in the living room on one of those dirty imitation-leather couches.* […] *She came in and sat beside me, just like that, and really, the only thing she did was just putting her hand on my knee, saying: "This must be horrible for you".* (EH)
>
> The worker in this example provided emotional support, responding to an observation of seeing EH suffering and expressing her compassion. The worker literally and figuratively 'touched' EH. EH remembered this act of recognising and acknowledging her suffering for the rest of her life. I elaborate on these acts in the next chapter.

[26] Van Heijst (2005) noticed that care receivers do not only have a short-term response but also a long-term response when the care receiver becomes a 'care leaver' and when the receiver looks back at the past. Van Heijst says that the long-term response often has a character of (moral) judgement, because the care of before has become part of someone's life story and biography.

Professionals who have a more long-term involvement make three mayor contributions. Firstly, they play an assistant role in the *management of the personal niche*. They help the person to become and/or remain in charge. Whenever there is a moment during which the person has a setback, they help to restore their personal space. In order to secure this role, they are faithful and reliable.

Secondly, they play a role in *development*. They keep on supporting the process of orientation by providing hope, setting goals, making plans and realising ideas. They help the person to increase his or her strengths and to develop skills and talents.

Thirdly, professionals play an important role with regard to social recovery, the reconnection to the world. They represent the 'ordinary world' as a person (being able to work, being useful to others, having social roles in different life domains). They serve as a model or an example. They also help in the process of reintegration, for example by supporting the person to enter new environments and roles.

Professional support

As in the case of natural support, professional support does not always have to be face to face. The idea that the support is accessible and available is already supportive.

For DG it was adequate to know he can reach his case manager. She was literally 'within reach' in the palm of his hand, with her number on his mobile phone.

> *What is helpful for me is that I can reach Y [case manager JPW]. I have a mobile with me, and her number is programmed in it.* (DG)

Some types of support are incidental, but can have a great impact. Others are valuable by the virtue of durability or permanency. Sometimes this durability lasts throughout one particular important period, such as the whole period of stabilisation or reorientation.

FJ said she had been lucky to find the right professionals throughout different stages of her recovery process. In times of crisis and stabilisation she met a social psychiatric nurse with 'special qualities'. He was working in the general hospital where she was admitted to be treated for her physical injuries.

> *The one who supported me most in the hospital was a social psychiatric nurse. He was just there for me. […] He just remained himself, he had a great sense of humour, he immediately said everything he was thinking, so he was a very transparent person, and also safe. […] He came to my bed every day, because I wanted this. So even he was very busy and had many clients or whatever, he came for 10 minutes anyway.* (FJ)

In the reorientation phase, she met a psychotherapist who helped to rework her experiences.

> *That psychotherapist just had a practice at home. It was a small farm with a little garden house in the garden, and yes, she was really just like a mother.*

In the reintegration phase, she was lucky enough to meet a vocational rehabilitation worker with the qualities suited to her support needs.

> *If it was going bad with me, I could just meet him in-between. […] And I didn't have to say anything. Then I could just cry and yes, he knew exactly what was going on. Yes, that's just luck. Those kinds of people you just have to meet by chance.* (FJ)

Other supportive relationships last throughout a large period of life. This is mostly the case with close family members, like in the story of SW, whose sister had already been a valuable resource for him for 30 years. SW also had a psychiatrist whom he had known for almost 15 years.

> *I might call her my long-term psychiatrist; I had a long [period of] group therapy with her, with intermissions, but I could always return to her.* (SW)

Many of the participants in my study had had long-lasting relationships with professionals. They were especially there as 'watchers', as DG puts it, to help take care of their personal niche.

> *YH,*[a case manager JPW] *yes, she has supported me awfully well. And she is still watching over me. And EH* [another case manager JPW] *too. They have helped me very well. And I can go to them any moment, if I need them, I can go to them. […] I have known them for years now. Five years.* (DG)

Characteristics of good caregivers

In the section above, a number of notions are mentioned that seem to be important elements of good care. It seems that professionals who are valued for their contribution to the lives of the people they are serving have a number of specific qualities.

In summary, good caregivers

- are acting in an open and respectful way, taking the other seriously as a human being;
- are being susceptible on an emotional and communicational level;
- are acting in a sensitive and responsive way with regard to the needs of the other; in many cases they fulfil the primary needs of attention, safety and belonging, and the affirmation of human dignity;
- are able to connect
    - to the person on a relational level
    - to the needs (giving what is necessary and what is needed)
    - to the process;
- work in a 'complementary mode', meaning that what a person can do him- or herself is not taken over, but that the professional adds what a person cannot do to support himself at the present; working in a 'complementary mode' also means being complementary to the needs of the other;
- are mobile and flexible;
- are acting in a positive way; they offer inspiration, create perspective, and have an eye for the good and for possibilities;
- are loyal and trustworthy, remaining present in the life of the person;
- are acting in a way which is strengthening the person with regard to his or her identity, his or her ability to take care of the vulnerability, his or her self-confidence and social reintegration; and
- place a client above the rules and norms of the institution, are able to 'do something different' or 'do something more' than standard procedures prescribe, and thereby are able to respond in a flexible way to the needs of the client.

When looking at the elements mentioned above, one notices that when they are regarded separately, most of them are *not* professional by definition, in other words, any person can be a 'good caregiver'. However, the combination of elements and an ability to use this in attunement to the unique individual requires a vast area of competences. Furthermore, when put in a professional context, the elements are placed in the framework of a service relationship. Participants in this study indicated that a kind of 'personal–professional' relationship gave them a number of advantages. It gave them a clear frame of reference for the relationship, knowing that the professional can never become involved in an intimate relationship and will abstain from trespassing personal boundaries. Since the main task of the professional is to help the other, and since he or she is paid to do this, the client can make a legitimate appeal to the services and does not have to return favours, as may be the case in other types of relationships. Finally, since the professional is part of a larger team or service, this provides the security of back-up in case this is necessary.

In the next chapters I elaborate on these insights.

What makes the difference?

My analysis confirms the findings of the studies of Topor (2001) and Topor *et a*l. (2006). Topor *et al*. (2006, p. 27) state: "The professionals described in the interviews [...] did *more* than their formal role required; and they did something *different* than what the person had come to expect from professionals" (italics by JPW).

DG made an interesting distinction between
'real care workers' and 'people that help you'.
In the following dialogue I was looking for the difference.

> DG*: I've had so many care workers. But some are special; they just got it. […] They feel you. Yes, feeling. You get understanding. You have a problem, and they understand it! And they can talk about it. And they also say it just like that: "You're an asshole", and I accept this, because I am. They can say it because I know them and trust them. Yes, they know my entire background. They trust me too. I talk about it confidentially. […] They trust me and I have taken them into my confidence. The others, the real care workers, are more outside of you. But those few people help you.*
>
> JPW: *It's interesting to notice that you make a distinction between real care workers and people that are helping you. It seems that not all care workers help you.*
> DG: *No, they do their job. And others have understanding for you.*
> JPW: *One could say that the people who really mean something to you simply do their job as well.*
> DG: *Yes, but they do something more.*
> JPW: *Do they do their job better?*
> DG: *The others do their jobs, from 8 to 5. The others you can reach any time.*
> JPW: *Yes, but one could also argue that they do it because they are paid for it. That it is part of their job. To be accessible.*
> DG: *Well, no, it's more; they just have that extra.*

Doing more

Doing more and doing something different are relative understandings. People perceive behaviour of 'really helpful' professionals as different, because they relate this to previous experiences with other professionals, or with general images about what a professional should do and not do. Hence, socialisation in a certain 'professional culture' plays a role here.

Doing more than a formal role requires says something about how roles are defined by a professional organisation and perceived by a person meeting a professional in a particular role.

In the study by Topor and colleagues (Topor *et al*., 2006), participants talked about the importance of clinicians or other professionals going above and beyond what is expected of them. To do more meant that the professional did what he or she was employed to do, but performed these tasks so thoroughly that the person sensed that something unusual had occurred and felt the professional had gone above and beyond the job description. In the interviews, two themes reoccurred in relation to this issue: receiving more time and more attention than the person came to expect on the basis of earlier experiences; and being chosen and being treated in a special way).

These examples also emerged in my study, as shown by the next citations.

> *I sensed I needed something more than just the regular help from my case manager. So my case manager really looked around, with me, and she found someone. She was sure that this was the right person for me. But the problem was that this therapist was working outside the mental health region, and this was not allowed by the mental health service. My case manager phoned over and over again, and in the end, she succeeded to get permission. This alone, that someone is making special effort for you!* (EH)

> *Once I had a very tough time. I called him and cried, cried, cried. And then he drove to me the very same day, all the way from V.* [a town at 35 km. from her house JPW] *I said: "Do you really want to do this? Are you really coming to me?" He said: "Sure, I feel so sorry for you that I'll come to you at once".* (MR)

> *T.* [clinical psychologist JPW] *put extra energy in me. […] He said: "There is much more in you than you show. I can't let you stay at the crisis unit". […] Then I got a lot of attention, and professional help. Instead of once a week, I was getting two sessions a week, and sometimes even more! Then suddenly I was getting a perspective.* (GK)

From these examples, a number of elements of good care appear: making extra effort, believing that this action is beneficial for the person, sensing and acknowledging the need, and having compassion and acting in an unconditional way. Extra effort also refers to the amount of time spent. The people not only regard the amount of time spent as beneficial, but also experience it as 'this is done especially for me'. The other is conceived and valued as being important, acknowledged as a person, a human being whose health is at stake. It is care tailored to individual needs, embedded in a caring relationship (I expand on this notion in the following chapters).

Doing something different

Within mental health care and other types of institutions, roles and relationships are the results of socialisation and culture. In mental health care, the history of psychiatry as a medical discipline plays an important role. The doctor, nurses and other staff who work in an institutional culture exercise a model of professionalism characterised by vertical relationships, the dominance of the professional as the expert, the professional in power and 'professional distance' as a virtue. Professional work is embedded in regulations and routines. Over the past decades, managerialism, market thinking and cost-accountability have been added to these routines, and severely influenced daily practice (see e.g. Petry, 2007; Tonkens, 2003, see also chapter 5). It is against this background that clients notice when a professional behaves differently from the norms of the profession or that the institution he or she works for prescribes.

> *And yes, what I will never forget is that I said: "I don't like life at all. Now and then I don't like it, life, then I am just fed*

up". And that he said: "But I have the same, I don't like life every day". And that was exactly the right thing to hear. (MR)
According to the rules, she had to stop psychotherapy after one year. But she found a way to go on, putting our sessions under another title. (PV)

She had to make a plan with a diagnosis. But I didn't want to know anything about this, because at that time I was very sensitive for any label […]. So for me it made me stress even more, and very unhappy. She supported me also with this by saying: "OK, I will take care of that plan, the paperwork". So that also meant that she had to deviate from the existing rules. […] This released me from a lot of pressure. (PV)

My psychiatrist was interested in alternative ways of healing. For instance, she saw the importance of meaningful rituals, which she derived from Indian tribes. (SW)

When a professional does something different, he or she emerges as a real person. The relationship with the person ceases to be a neutral one. A certain emotional involvement becomes part of the relationship. Often, clients perceive this as a personal relationship, which has the traits of a friendship.

He is close to me […]. For me it was very recovering that he made an exception, just for me. He said: "You're special enough", […] meaning something like you are worth it. (FJ)

It is quite clear that people can distinguish friendship in a professional context from friendship in an ordinary context. In Chapter 5, I discuss the notion of friendship in a discourse of good care.

3.13 Conclusion

The analysis of recovery factors in Chapter 2 showed five clusters or dimensions:
1. Factors that provide personal motivation to initiate recovery and to move forward
2. Factors belonging to the development of competency for coping with the illness and the environment
3. Factors contributing to the reconstruction of the identity
4. Factors of social engagement
5. Environmental factors that serve as resources for recovery

This study confirms that these are meaningful clusters. However, an intriguing question is how factors interact with each other and which patterns of interaction promote or hinder recovery. Although it is reasonably clear which factors contribute to recovery, it is not yet clear which factors *in collaboration* instigate a transition. In paragraph 2.10 I hypothesised that if the different elements *synchronise* in order to enforce each other development takes place. It is, however, not clear which factor (or when a factor) contributes more to recovery than another factor. Some people seem to build strongly upon their personal cognitive strengths, while others seem to respond mainly to the efforts of others. It is also not clear when factors tend to exclude or extinguish each other. More research needs to be done in this regard.

From the analysis two sub-processes of recovery appeared. One is the process of *personal recovery*, which consists of two main tasks: (1) gaining control and taking care of

vulnerability; and (2) developing identity. This sub-process leads to (more) self-control, and to a stronger or more integrated identity. The other sub-process is the process of *social recovery* or the process of social (re)integration. The task here is to work on social integration: becoming part of society.

When looking at the data from this study on transitions, one notices that different types of factors contribute to progress. Factors that influence progress in one area, for example the area of vulnerability, influence factors in another area, for example identity or social functioning. Factors can be divided into intrapersonal factors (such as cognitive abilities and self-confidence), interpersonal factors (such as the presence of a support person) and material factors (such as medication or housing).

There are however no 'standard constellations'. For every participant in the study it was the amalgamation of a unique combination of factors in a certain period of time which lead to a positive transition. A transition is marked by a change that is induced by desire, courage or an opportunity. This change is empowering: It provides the person with acknowledgement, affirmation and new energy.

Another discovery from the narratives is that the area of taking care of the vulnerability is the first area in which recovery has to take place. It forms the basis for the other areas of recovery, the areas of identity and autonomy, and the area of social functioning. This corresponds with the phases of stabilisation, reorientation and reintegration.

Some participants in the study struggled to adapt to the disability (Cluster 2 of the model in paragraph 2.8); others made progress in the area of developing identity (Cluster 3). The notion of autonomy is defined in the narratives in different ways. It can be regarded as being able to manage the disability well. It can also be regarded as being able to make decisions independently of others. A third connotation is to be able to use capacities in valued social roles. Autonomy is connected to a shift from an illness identity to a 'person' identity, and to growing independence.

The concepts of personal niche and social niche can be regarded as two constellations of favourable factors. The personal niche is a constellation of factors contributing to the management of the vulnerability. The social niche is a constellation of factors contributing to identity and social reintegration. Both types of environments contain intrapersonal, interpersonal as well as material factors. It seems that these constellations of factors are stress-reducing as well as supportive for identity formation and social functioning. In the next chapter, I explore the elements of a habitat suitable for recovery on the basis of basic notions.

It seems that the professional caregivers that featured in the narratives played a role in the three areas of recovery (decreasing vulnerability, reconstructing and developing identity and improving social functioning). Some professionals only played a role in one of the three areas; others supported development in all three areas.

The narratives in this study reveal factors that make professionals valuable resources. An important finding is that interaction characterised by a trustful relationship is *in itself* a cherished resource. The professional must be perceived as someone who is reliable and can

be trusted. I elaborate on the concept of trust and related notions in Chapter 4. In addition, the professional as a resource should be connected to a person's need and contribute to the fulfilment of this need. This requires careful understanding of what is important for the wellbeing of the person. Sometimes, this contribution is 'only' moral support, in the sense of being present being enough; sometimes the contribution involves some kind of action, such as solving a problem, helping with the household or keeping the budget. For the person it is important that the other is perceived as valuable. For the professional it is important to be able to relate to the person as an individual, in the context of his or her present situation and his or her personality and biography, and to be able to connect to his or her individual needs. In the next chapter I present a secondary analysis of the narratives in a search for basic notions that constitute the profile of a 'valuable professional'.

Chapter 4 Elements of good care

In this chapter, the results of a secondary conceptual analysis of the narratives in the previous chapter are presented. Compared to the next chapter, where I work mainly inductively with the data, the methodology used in this chapter is predominantly deductive by nature. In this analysis I looked for basic notions in the interaction between the narrators and professional caregivers. I searched for notions in the stories that were associated with good care.

4.1 Introduction

By using the constant comparison method of grounded theory, notions could be revealed that are important in most of the narratives. These notions could contribute to the development of concepts and theories about recovery-oriented care, or more broadly, a discourse of good care. In this chapter I present the notions as derived from the perspectives of the users of care. In Chapter 5, I transfer these notions to the perspective of the professional, using them as foundation for a discourse on good care.

From my analysis, many different notions emerged. Table 4.1 presents these notions in alphabetical order:

Table 4.1: Notions identified from the narratives

Acceptance	Moving along, being flexible
Acknowledgement	Perceiving/Perception
Affirmation	Personal connection, contact
Availability	Personal qualities
Attachment	Perspective
Attention/Attentiveness	Positive focus
Clarity, transparency	Presence, being there
Comfort	Reassurance
Commitment and dedication	Reachableness
Confidence	Reciprocity
Connection	Recognition
Contact	Respect
Continuity	Responsiveness
Dialogue	Room/Space
Empathy	Security, providing safety
Equality	Seeing, being seen
Experience/Experiencing	Sensitiveness/Susceptibility
Expression	Strengthening
Identity/Identification	Time
Inspiration, encouragement, motivation	Togetherness/Companionship
Learning	Trust(worthiness)
Listening	Understanding

After performing a cluster analysis, five meaningful categories were found. These are the following:

1. Connecting
2. Understanding
3. Affirming
4. Securing
5. Strengthening

The categories are characterised in terms of active verbs, to indicate that it entails an active and dynamic process. From my analysis it became clear that from the perspective of the person, the meaning of a caregiver is seldom restricted to an isolated action. Good, sustainable care develops over the course of time.

The *first* category is that somehow a personal connection is established. Although it is a separate category, consisting of a number of elements, the connection can only develop and obtain meaning through the acts within the other categories. The *second* category is that a person feels understood. This can be an understanding of the situation or of him- or herself as a person. Feeling understood strengthens the personal connection with the professional. Another important act is that the person has the experience of being acknowledged. This constitutes the *third* category. Again, this may be an acknowledgement of the personal situation, but also of vulnerability and strengths. By this recognition the person feels seen and respected. I have chosen the term 'affirming' to express that by being recognised and acknowledged (especially), people in vulnerable dispositions experience something to hold on to. Being recognised as a unique human being means that one's personal identity is revealed and affirmed. At the same time, it is an expression of value and an important element to increase self-confidence. The *fourth* category is securing. Although affirming is also a form of securing, securing encompasses all elements that help the person to feel safe (or safer). From my analysis it became clear that the mere presence of a professional who is trusted by the person and who offers companionship provides the needed safety. Different active forms of securing came to the fore in the study. This varies from a quick response to a desperate phone call to setting up an early warning-sign or crisis plan. The *fifth* category is called 'strengthening'. From this study there is overwhelming evidence that good care is aimed at making people stronger and helping them in their recovery or development process. Strengthening starts with recognising the strong (healthy) side of the person and focusing on possibilities. Clients value professionals who have an optimistic point of view, who provide encouragement and inspiration. An important form of strengthening is supporting people to learn from past and present experiences.

Of course these categories are interconnected. Although some specific elements of making a connection can be identified, a personal connection is also established or reinforced by acts of understanding, affirming, securing and strengthening.

In the next paragraphs I describe the categories and the notions belonging to these categories. The chapter is concluded with a paragraph on the relationship between the categories and a conclusive summary.

Reading tip: The findings of the analysis are presented in a condensed way. The findings 'come alive' through examples and citations from the narratives. Details of the five categories, accompanied by examples and citations, can be found in separate parts, which can be recognised by a smaller font and a two-column layout. The reader who is interested only in the conceptual findings can simply skip these parts.

4.2 Connecting

Connecting is the process of establishing a connection. If this connection goes beyond being merely a connection, we might speak of *connectedness*. By connectedness I mean that the recipient experiences a personal connection with, or attachment to the caregiver.

In the category of connecting, two sub-clusters can be identified, namely a sub-cluster of *immanent notions* (paragraph 4.2.1) and a sub-cluster of *communicational notions* (paragraph 4.2.2). Together, these sub-clusters constitute what I call an *interpersonal space* (paragraph 4.2.3). This is a psychological and phenomenological space that is an expression of the connection and that provides room for interaction and development in terms of the other four main categories.

4.2.1 Immanent notions for a personal connection

Immanent notions for establishing and maintaining a personal connection are the following:

- Contact
- Empathy and sympathy
- Attention/Attentiveness
- Respect
- Equality
- Availability/Time
- Moving along; being flexible
- Commitment; dedication
- Positive focus
- Continuity
- Togetherness (companionship; sharing)

In the next table the notions are first summarised and then clarified and illustrated with examples from the narratives.

Table 4.2: Notions belonging to establishing and maintaining a personal connection

- *Contact:* the feeling that there is a 'click'; feeling good, safe, feeling confident with each other; liking each other; liking the caregiver; the caregiver having sympathy for you; using humour
- *Empathy:* feeling that the other is able to place him- or herself in the client's perspective

- *Attention:* receiving personal attention; being attentive to my needs; giving undivided attention; receiving warm attention; receiving perceptive and observant attention; really listening; attention as a gift

- *Respect:* respecting me as a person; having mutual respect; respecting autonomy; accepting me as a person; accepting my situation as it is

- *Equality:* being on the same level; being treated in an equal way, despite differences in knowledge and position (power balance); being on an equal level (dialogue); giving and taking; mutual trust and confidence; reciprocity in the relationship; not only focusing on me as a client, but also on himself as a professional; being self-reflective, which is important to ensure a good relationship

- *Availability:* being there (especially) for me; being available, reachable (being able to reach the professional physically, psychologically and socially); being accessible

- *Time:* taking time; having time; giving time; no time pressure; timing: the right thing at the right time; focusing on process and duration (developments sometimes take a long time)

- *Moving with:* being flexible: walking together on a path, adjusting to my pace; attuning to my experiences; being flexible; finding solutions beyond rules and regulations

- *Trust:* experiencing feelings of trust and confidence

- *Commitment and dedication:* being involved with me; being committed to my case; doing something for me; making efforts on my behalf; remaining faithful and loyal; being reliable; carrying me through tough situations; Synonymous with: involvement; engagement; devotion; perseverance; loyalty

- *Positive focus:* on possibilities, my qualities, achievements, the healthy side; believing that my situation will and can get better; believing in my strengths and possibilities; focusing on progression

- *Continuity:* remaining there; remaining there in difficult times (mostly meant in a psychological sense); continuing to visit me, even at the time I did not want it; staying connected for a long time; being available, walking along
Continuity in the meaning of congruence: sayings and actions are synchronised; being/remaining in contact (when necessary)

- *Togetherness:* feeling of togetherness, of companionship; sharing information, my suffering; personal facts; personal experiences; sharing common interests; togetherness in action (e.g. drinking coffee, setting up an action plan together; working on improving skills for handling situations); being like a friend; being close; having someone to share things with; having someone as a friend.
Note: in this form of companionship there is *reciprocity*: giving and taking; a situation of mutual trust and confidence. This also includes being able to have disagreements.

A personal connection

'Helpful professionals' are apparently able to make a connection between two frames of reference, that of the client and that of the professional. 'Personal' is a word that was often used in the narratives. SW expressed this as *giving something of yourself*. This can refer to sharing personal experiences or using the own person as a point of reference.

> *The people who share something personal are very special, like the nurse who confided in me that she once had been so overwrought that she wanted to throw her children off the stairs.* (FJ)

Experiencing a personal connection means that a form of 'attachment' is established. The person and the professional become attached. The attachment provides social interaction, security/structure, a sense of belonging and the fulfilment of more specific needs. This is more than a functional attachment defined by a care-receiving versus a care-giving position. A connection is formed on multiple levels. Apparently, the professional succeeds to connect on a personal, relational level and/or on the level of his or her operant behaviour, and to respond to the needs of the person in a way that is perceived as supportive.

There are a number of elements that constitute this connection, which will now be reviewed.

The 'click': experiencing real contact

In many stories, participants spoke of a 'click', meaning that a convenient match was made between them and a professional. This is a personal fit, usually characterised by sympathy. Contact has a strong affective component.

> *I already said that I can immediately feel if somebody is acting purely out of professional expertise and for the rest without interest, where I am only a case, or if someone is really looking for personal contact.* (SW)

> *The core is that you like each other. […] There has to be a click. When you like each other then there is a click. This has nothing to do with how able that caregiver is. It's the human click.* (NS)

Sometimes this 'click' is already established during the first contact.

> *And then I got JS,*[social-psychiatric nurse JPW] *well, that was everything. It clicked immediately. I remember when he visited me at home for the first time. And I really had the feeling that I'd known him for longer than that day.* (MR)

Contact is also related to time. Contact can have an instantaneous character, like a 'contact moment', or a long-lasting character, as in "We have already been in contact for a long time".

> *I have known my psychiatrist for a long, long time. […] It was more than client–psychiatrist contact.* (SW)

If it has an instantaneous character, the value is often attributed to the fact that there was a personal connection and something was said or done that was meaningful at that moment.

> *She came in and sat beside me, just like that, and really, the only thing she did was just putting her hand on my knee, saying: "This must be horrible for you". (EH)*

Sympathy

A number of participants indicated that the core of having a good connection is that the parties like each other. The person experiences feelings of sympathy; however, it

is not easy to say which exact factors contribute to this feeling.

> *Right when we met for the first time, he seemed a very nice man to me. Right away I had the feeling: Yes, I can be myself with you, so that's very nice.* (MR)

> *I don't know; it seems that we had the same kind of humour and straightforwardness.* (MR)

The use of humour or remarks that cause relaxation seems to be one of these factors:

> *We had the same sense of humour. He said: "This is very good, that even now you are wrecked, that you still have your humour". Yes, that keeps you going.* (FJ)

In situations where the person feels tense an insecure, meeting another person who is able to relieve tension by radiating calmness or making relativising or reassuring remarks, is perceived as beneficial and makes a person sympathetic.

> *He was just sitting there in my living room. Very relaxed.* (MR)

I connect this professional behaviour to being part of the category of securing (see paragraph 4.5). People who have needs that are connected to basic security experience a professional who is able to address this need as beneficial.

Empathy

Establishing a connection is facilitated if genuine empathy is experienced. Empathy refers to the ability to place oneself in the position of the other and to identify with and understand the other person's situation, feelings and motives.

> *Yes, yes, empathy. You have people who pretend to have empathy but in fact they don't. I feel that. It is not sincere. […] Yes, I believe […] that I am authentic when I am in good shape. That's for me a standard. […] You also need to have social intelligence, and timing, but authenticity is very important.* (SW)

> *People have to be understanding, and emphatic.* (KP)

Here there is a connection to the category of understanding. Professionals are experienced as empathic if the person feels that there is some understanding of his or her situation.

Respect

Respect is expressed as respect for someone as a person, mutual respect and respect for autonomy. Respect is also associated with *acceptance*: accepting someone as a person and accepting his or her situation as it is.

In most narratives, the participants emphasised the importance of being taken seriously. Not only should the problem be taken seriously, but also the other as a person.

> *I felt being taken so seriously by him, and that makes a great difference.* (MR)

> *That's what it comes down to. You want to be seen as full, to be taken seriously.* (NS)

I relate respect to the notion of recognition, which I categorise under the category of affirming (see paragraph 4.4). By being taken seriously, the person is acknowledged as a worthwhile human being with his or her own life, experiences and expressions. By giving affirmation, this basic need is responded to, whereby a relationship is constituted.

Attention/Attentiveness

Attention is expressed in terms of receiving personal attention, giving undivided attention and receiving warm attention. The adjectives 'personal', 'undivided' and 'warm' refer to qualities. 'Personal' refers to personalised attention. The attention is not general attention, but it is focused on *the person*. This makes the attention special and unique. The attention is 'undivided'. 'Undivided' can also

mean that the person is approached as a whole, as a whole person; the attention is not focused on just one part of the person (e.g. his or her problem or disability).

Attentiveness is a notion that precedes attention itself. It is the ability of a professional to attend to the attentional needs of the other, which makes it possible to adapt the form and type of attention according to what is important at that moment. Attentiveness is appreciated if the professional is attentive to the person's needs, is perceptive and observant, and if he or she really listens.

Attention can be qualitatively described as being *caring* and *careful*. Through the way attention is given, a concerned attitude is shown.

Attention does not always have to be given verbally. It can also be shown through activities, for example by handing someone a cup of coffee.

Perceptive and observant attention also forms the gateway to gathering information about the person and his or her concerns and demands. Attention is given to the needs of the person, and is connected to responsiveness.

Attention is also connected to the art of *listening* (see "communicational notions").

Some participants told stories in which they were given attention without asking for it. Although they did not ask for it, the attention was still very welcome. One could say that the need was not articulated, but that it was there in a latent form. Once attention was given, it was experienced as something beneficial.

Other participants told that they had asked or even begged for attention, some even in a very dramatic way, for example by attempting suicide, as in the stories of FJ and KP. In these situations, one could say that even violence was used to get attention. This illustrates the great relevance of being sensitive to the need for attention.

Professionals can easily be distracted, for instance by other people or tasks requiring their attention. But the professionals who have been qualified in the narratives as being attentive apparently manage to give individualised attention despite other things requiring their attention.

Baart (2004, p. 17-24) lists three types of attention: "to have attention", "to give attention", and "to direct attention". To have attention can still be rather neutral. Something has your attention, but this says nothing about what will happen next. To have attention also refers to concentrate on something or someone. To give attention takes some effort. It costs something, like vigilance or energy, to concentrate on listening carefully. To *direct* attention implies that attention is not automatically or by its self focused: it must be 'gathered' and purposefully oriented, given a direction, so 'directed'. Its nature is 'capricious', which means it tends to escape, to dwell. Apparently, professionals experienced as 'good professionals' know not only how to have attention, but also to direct and to give attention.

Equality

From the study it is evident that equality is greatly valued. The notion of equality is expressed in a number of ways: standing beside the person, being treated in an equal way despite differences in knowledge and position, being on an equal level, giving and taking and mutual *trust* and *confidence*.

Equality is expressed in the way the communication between the person and the professional is constructed (see paragraph 4.3). One requirement is that there is equality in the power balance. Although there is a difference in position, background and knowledge, these differences should not be used by the professional to exercise power.

> *Someone has maybe learned much more than you, a psychiatrist, but he is equal to you in a conversation. That's*

important, that it is an equal conversation. (RL)

Clients appreciate it when professionals share personal information or show their own feelings. A professional sharing emotions or becoming emotional expresses him- or herself as a 'real person'. It gives reciprocity to the relationship – a bond on a deeper level.
In the citation below, different factors contributing to equality come to the fore.

Yes, I feel tremendously at ease with him, because he also told me about his own relationship, about his kids and his wife. That they were making jokes sometimes, or having a discussion. […] It gives you the feeling that you are one, that he does not stand above you. I think that's very important in conversations. […] So, yes, I trusted him more and more. (MR)

In the communication, the focus should not only be on the client, but also on the professional him- or herself. It is perceived as valuable if the professional talks about his or her personal experiences. This provides a basis for equality, both being human beings who have witnessed and experienced a number of events in their lives.

Equality is related to the notion of reciprocity. There is no one-way traffic, but an exchange of ideas or experiences, or an act of giving and taking when it comes to activities undertaken to reach a specific goal. Without reciprocity there is neither a connection nor can a sense of companionship be created.

Most participants knew exactly how to 'use' professionals without becoming too dependent or becoming too personally involved.

It was more than client–psychiatrist contact […]. However, I always considered her as a psychiatrist, just to avoid the danger that other things .... that I could just use her services as a client whenever necessary. (SW)

Availability

Great value is attached to availability and *reachableness*. This is expressed as *being there* (especially) for the person and being available and accessible.

Being able to reach the professional is meant in a physical, a psychological and a social sense.

If it was going bad with me, I could just meet him in-between. Just in the consulting room. And I didn't have to say anything. Then I just could cry. (FJ)

Availability has to do with having *time* available. 'Taking the time' is associated with creating the space to be together, to pay as much attention as is needed. Time was mentioned in the narratives in terms of multiple meanings: taking time, having time, giving time, no time pressure, doing the right thing at the right time and staying with the person (over the course of time, which is connected to the notion of *continuity*).

I also had a nurse and she was very nice, but quite busy, so she was saying: "Come back later". While you needed it right then. (KP)

A lot depends on the time they have for you. […] A psychiatrist has maybe 60 patients. But my psychiatrist, I talk to him for at least half an hour. Minimum. Not 10 minutes. That's much too short. […] This is the time he takes for a conversation. (HM)

The length of time is not always related to quality. Some participants indicated that sometimes a short moment of contact is enough to meet their needs. This is mostly the case if a relationship has already been established.

If I was depressed, I just called him. […] And then I could go on. (MR)

It does not have to be a lot of time. Five minutes could do. (HM)

The way time is used specifically contributes to establishing a connection. Time has a number of subcategories, such as pace, timing and continuity.

> *It is very important that they take the time for you.* (RL)

> *You need to create time for having a good conversation with a patient. What is more important: to have a good conversation or to sit behind the computer?* (HM)

Reachableness is associated with availability.

In order to make contact or connect with people, the parties have to (be able to) reach each other. A professional can (try to) reach a client in many different ways, but should also be reachable by the client.

Reachableness has three meanings:

* Physical: A professional should be present 'in the flesh', in person, and should be reachable in order to communicate with and to be supportive.

> *He was just sitting there* […] *Being there for me.* (MR)

> *I could always phone him, which was also nice.* (MR)

* Psychological: Many clients value the idea that a professional is attainable whenever needed. In the context of the personal niche, the idea that someone in a support role with regard to the personal niche is reachable is reassuring.

Both meanings are related to the notion of availability. Although a professional might be good at his or her job, if he or she is not available, it is of no use to the client.

> *I have her mobile phone number, so I can always reach her.* (DG)

> *He had a mobile phone number and then I could always ring him. Yes, actually not over the weekend. But that was nice. Because if you had some trouble, a certain fear, you wanted to be helped at once. And then I could phone that man. I liked that. That you don't have to wait for one week, or two or three weeks. I think it is important that you can contact your therapist directly.* (RL)

> *She was always there for me.* (SW)

* Social: A professional should be reachable as a fellow human being to socialise with apart from fulfilling the professional role, and sometimes also as an intermediary to reach other people.

A professional should also be reachable in the domain of personal experiences and emotions. Participants spoke in terms of 'a vulnerable disposition'.

> *I think the most important is that this person stands beside you and not above you, and dares to be vulnerable.* (MR)

There may be situations in which a client actively looks for help. There may be other situations in which this is not the case. In the latter case, it is the task of the professional to reach out. Speaking figuratively, he or she might reach out his or her arms or hold out his or her hand to the person. HM gave an example of this:

> *I was just laying there, in my misery. Then he came to bring me a cup of coffee.* (HM)

It is a movement *towards* the other (instead of waiting for the other to approach or withdrawing, which is unfortunately a quite common experience of many clients).

Moving with

Mobility is related to the concept of reachableness. The movement of 'reaching out' or 'moving towards' is an example of mobility. Another aspect is to (be able to) follow a client along his or her life path and follow the steps he or she takes. Mobility also implicates *flexibility* – the ability to anticipate changes.

'Moving with' has several connotations, such as walking together on a path, adjusting to the client's pace, following experiences, being flexible and finding solutions beyond rules and regulations.

Moving with the person means staying tuned and connected.

> *So it helped me a lot that she was following me. That I was not being forced in a corsage: e.g. in a year you have to be healthy. Because the laws say that. But she was saying: "That's not how it works. We'll walk on our path, and we'll see". It was closely connected to my way, my pace, my experience.* (PV)

Moving with the person also means staying with him or her and not leaving him or her. The idea of mobility could also refer to choosing the right psychological distance, which can vary according to circumstances and needs.

> *Just withdrawing as much as possible, but yet being there for the other, yet being available.* (AD)

Trust

Another element of forming a personal connection is experiencing feelings of trust and *confidence*. There are different aspects that create this experience, such as confidentiality, as emphasised in the following citation.

> *It is important to take people into your confidence. […] You need someone to discuss confidential things with. That you can count on this person that it remains confidential, that's also very important.* (RL)

Trust is closely related to faith and hope. There is a belief that things will improve. Although trust can originate during the first meeting, over the course of time the professional has to prove that he or she can remain to be trusted. The professional has to show that he or she is worthy of the trust the client places in him or her. This is literally the meaning of the word 'trustworthiness'.

Trust is associated with loyalty and *faithfulness*. The person wants to know that the professional will remain loyal or faithful to him or her. This means that the professional remains present (*cf*. Baart, 2001; see Chapter 5).

There is a relationship between confidence and understanding. If the person feels understood, this gives *confidence* that the professional at least knows what 'it is about'. It is the basis of trust. Trust is an important cornerstone for working together. The client has confidence that the professional can be helpful to him or her. This can also help to increase the person's self-confidence. Here there is a connection with the category of 'strengthening'.

> AD talked about *the gift of the combination of reliability and professionalism*, which leads to trust. If someone is trusted it may lead to the confiding of personal issues to the professional.
>
> *People are really thinking: I dare to give you something. I dare to leave my fate a bit in your hands, because with you it is in good hands.* (AD)

The example above indicates reciprocity. The client gave something into the hands of the professional.

An act of trust is when a client confides certain information to the professional. The expression 'taking someone into my confidence' means granting someone access to your inner, private world. There must be basic trust in order to do this.

> *These people sense you. You get understanding from them. […] They trust me and I trust them. I speak confidentially with them. They take me into their confidence and I take them into my confidence.* (DG)

Many of the stories of the participants in my study are marked by a lack of trust. In this regard it means a lot to professionals if clients take them into their confidence and have faith in them. Clients are often damaged in their youth by mistrust, or they have been repeatedly disappointed by people they came across in the course of their life, mental health professionals included. For them it is quite difficult to trust someone. There is always the fear that the trust will be damaged and that they will be disappointed again. It is no wonder that many clients are very reluctant to become involved with care workers. This may be complicated even more by the demands of managing the personal space. This often includes vulnerability for emotional involvement. When you trust someone it means that there is some degree of emotional involvement, which can also be risky.

Positive focus

A positive focus appears to be an important aspect in the relationship between the professional and the person. It is a focus on possibilities, qualities and achievements: the healthy side of the person. It is an expression of the belief that the situation will and can get better. It is a belief in strengths and possibilities, a focus on progression. The professional believes (has faith) in the client, and believes that progression can be made.

> *She gave me the perspective that it would get better.* (SW)

A positive attitude breathes optimism and hope, notions that also came forward from the review in Chapter 2 as important fuel for recovery.

Commitment and dedication

From the narratives it appears that personal commitment is considered a valuable asset. This is expressed in many different ways, such as being involved, being committed to the client's case, doing something for him or her, making efforts on his or her behalf, remaining faithful and loyal and carrying him or her through tough situations. A number of other notions are closely related to commitment, such as involvement, engagement, devotion, perseverance and loyalty.

Commitment and dedication can be expressed in the form of efforts, perceived as 'extra' or 'specifically' for the person. Examples of this are given at the end of chapter 3 under the heading 'doing more' and 'doing something different.
Dedicated professionals are willing to give themselves fully, within the limits of what is possible, of course. Personal efforts are experienced in many stories as a beneficial gift.

The infinitive verb 'to give' is associated with the noun 'gift'. Some participants indeed considered what they had received as a gift. It was something special, something very valuable to them. Others spoke of certain professionals being 'gifted' and having special talents.

Continuity

Continuity manifested in the narratives in a number of forms, such as remaining there, remaining there in difficult times (mostly meant in a psychological sense), continuing to visit the person, even at the times it was not wanted, staying connected for a long time; being or remaining in *contact* (when necessary), being available and walking along. Continuity is also expressed in the meaning of congruence, when words and actions are synchronic and a professional does what he or she had promised.

Continuity is related to the notion of time, which was discussed in the section on availability. It concerns a focus on process and duration. Most of the professionals that featured in the stories had a long relationship with the person. In many cases, their relationship with the person spanned many years.

> PV received a great amount of support from a psychotherapist. *And in the meantime, two and a half years after that crisis, we are still going on. But that's just the time that is needed.*

PV also had a special relationship with an art therapist in the rehabilitation centre, which helped him to develop his artistic talents, thereby rebuilding his self-confidence.

There may be circumstances in which a professional has to end the relationship with a client, such as for example when changing jobs. In such cases, good care also includes ending off the professional relationship carefully. MR provided a good example of this:

I really have difficulties with goodbyes. When J. [social-psychiatric nurse JPW] *was leaving for another job, I really had a hard time. He explained to me: "You have trouble to attach to somebody, and once you are attached to someone, you have difficulty saying goodbye". […] It took quite some time to get used to the idea.*

Although J. had ended his professional relationship with MR, they still had a kind of personal connection, as he asked her to keep him informed about the results of her studies. He also found another professional whom he believed to be a suitable care worker for MR.

Continuity is important with regard to the process dimension of a recovery or development process. Continuous support means to follow the client along his or her personal path Continuity also concerns maintaining a relationship as long as needed.

What benefited me was the fact that after my admission I could stay with the same psychiatrist for a couple of months. […] until a good psychotherapist was available. (PV)

By being and staying present and sometimes persevering if the person is not yet ready to make a connection, opportunities can be created for an engagement.

NS talked in favour of professionals who persevered with trying to reach him in times when he had pushed them away.

One could speak here of *continuous outreaching efforts*.

Since many recovery processes take a long time, it takes a lot of courage and *perseverance* to go on, not only from the side of the client, but also from the side of professionals. It is often a process of ups and downs, of three steps forward and two steps back. Hope and beliefs can help to hold on, and so does continuous support from others, including professionals. Perseverance from the side of professionals is associated with continuity of presence and remaining loyal in good and bad times.

NS ascribes his pushing away of professionals to the stage he had been going through at that moment. *You keep on resisting, until you have moved to a point that you have to admit it. It is a kind of internal struggle […] to accept that you are ill. […] As long as you have this internal fight, recovery is an illusion. […] I didn't like the care workers at that moment, but I appreciated that they kept on visiting me at moments that I really did not want it. [...] at that moment I had the illusion that I was not ill. But they persevered. So I gave them a second chance.* (NS)

It is clear from this example that it is appreciated when professionals remain present or keep on presenting themselves in the life of the person – even if the person resists the contact. The professionals use an *outreaching* mode of working. In NS's case, they came to his house, and even when he refused to open the door, they kept on coming, in a calm, friendly and concerning way.

Another example comes from FJ, who mentions a professional who had become very dear to her. *Even when I was depressed or completely psychotic, he said all the time, "Yes, you still need to have a goal". Yes, that's typical of him. He was just persevering.*

Perseverance is associated with commitment and dedication.

From many stories a feeling of *togetherness* comes to the fore, which resembles *companionship*. The notion of companionship has the following connotations: being like a friend, being close, having someone to share things with and having someone as a friend. In this form of companionship there is reciprocity: giving and taking, a situation of mutual trust and confidence.

> *He often just talked about ordinary things. Just nice things. I sometimes felt as if he was a friend and not a therapist.* (MR)

Within this companionship, different things are shared, such as information, personal facts and experiences. Togetherness also implies the notions of equality and reciprocity, expressed in the sharing of common interests and togetherness in action (e.g. drinking coffee, setting up an action plan together and working on improving skills for handling situations).

Togetherness expresses the feeling of clients that they have a good relationship with a caregiver. They enjoy a form of companionship that is experienced as beneficial. These caregivers give something personal, or something 'extra', beyond what is usually expected within the realm of their tasks.

'Personal' is a word that was often used in the narratives. SW expressed this as *giving something of yourself*. This can refer to sharing personal experiences, or using the own person as a point of reference.

> *Very special are the people who are sharing something personal, like the nurse who confided to me that she once has been so overwrought that she wanted to throw her children of the stairs. (FJ)*

Experiencing the caregiver as a kind of friend should not be confused with ordinary friendship. By keeping clear boundaries, safety and understanding are ensured.

> *I considered him as more of a friend than a therapist. […] I also told him: "I really see you as a friend". He said: "No. I am not you friend, I am your caregiver". He was very clear about this. I didn't like to hear this (laughs), but it is very good that he was clear on this.* (MR)

4.2.2 Constructive communication

A vehicle for establishing a personal relationship that produces favourable outcomes for the person is what I call 'constructive communication'. Constructive communication helps to establish a connection, adds to the quality of the relationship and also supports the recovery process. This type of communication should be maintained throughout the relationship.

Notions belonging to constructive communication are the following:
- Dialogue/Conversation
- Asking
- Listening
- Clarity – professional being clear
- Clarity – helping the other to express him- or herself
- Sensitiveness and responsiveness

In the next table different aspects belonging to these notions coming forward from the narratives are listed. In the box after the table this is elaborated and exemplified.

Table 4.3: Notions belonging to constructive communication

constructive communication	*Valuable elements seen from the perspective of the person*
Dialogical conversation	having a good conversation; having a dialogue; maintaining communication; remaining in consultation; talking about ordinary things; getting feedback
Asking	about my personal experiences, beliefs, intentions – wondering how things are; asking questions helps to tell my story; helps to (re)construct what has happened and to get better insight
Listening	really listening; listening well; listening carefully
Sensitiveness and responsiveness	perceiving the professional to be sensitive towards my situation and needs (by the way he responds to my feelings, my needs)
Being clear	experiencing the professional as open and transparent about intentions; about boundaries; about personal norms; being congruent; providing insight into the motives of the professional and providing structure;
Room for expression	helping me to express myself; telling my story; helping me to explain myself; providing room for emotions. Note: this concerns an articulation of experiences, needs, and ambitions. From the part of the professional it also includes discerning own feelings or opinions.

Dialogical conversation

In many of the narratives, the quality of the conversation between the client and the professional is emphasised. Participants talked about having a good conversation, having a dialogue, maintaining communication, remaining in consultation, talking about ordinary things (meaning other things than merely discussing the problem) and getting useful feedback. I summarise this in the notion of *dialogical conversation*.

A dialogue may be described as a conversation in which there is a search for mutual understanding. This understanding has multiple communicational levels, since the dialogue constructs both the relationship and a helpful perspective to advance the situation of the person. The notion of a dialogical conversation is related to the notions of equality and reciprocity.

There is an opportunity to express thoughts from both sides. I have previously used the words "open dialogue" to indicate what I consider to be the optimal mode of communication (Wilken and Den Hollander, 1996, p. 28). Of course this is an ideal situation, which is usually not there during the first contact. A dialogical way of communicating will grow only on the basis of trust and confidence.

> *Yes, he is just very human. You often have a doctor–patient relationship, with a certain hierarchy, but with him it is just a kind of open consultation. […] If I want to*

change something about my medication, then he is open to it. (AD)

This psychiatrist held me in respect. […] He advised me. […] Sometimes I wanted to drop a pill, just to try, but I really did it in consultation and not on my own. But he did not give me reason to experiment myself. […] In good consultation. Yes, that went fine. (BE)

It seems that the way the professional communicates is characterised by respect for the client's own ideas. The client is left in charge.

When it was not going well, they said: "It is not going well with you, but what do you want to do about it?" Conferencing, deliberating, very important. Not just doing something. (GK)

Nothing happened without [my input]. They involved me in everything, even if I was very psychotic, but also asked my consent. My parents also liked this, that they were involved. […] You have the idea that you're on the same level. (KP)

A constructive dialogue is enhanced by the way professionals ask questions, listen and provide feedback (responsiveness).

Asking

Asking concerns both the way things are asked and what is asked. An open, curious and sensitive attitude seems to be important. The professional should be really interested and should really want an answer from the client.

In the story of NS, he mentioned that he was sensitive to *tone*, i.e. the way in which professional care workers asked questions. *I am very sensitive to tone. And you can hear if someone makes a cynical remark, or when it is an interested remark. Or when it is a concluding question: someone is actually not asking anything. Well, then you've come to the wrong shop. If you are asking me something, then you have to expect an answer from me. You don't have to fill in beforehand.*

In a dialogue, questions and answers have the function of obtaining better understanding.

Listening

The quality of *listening* is expressed in phrases such as really listening, listening well and listening carefully. It is connected to the notion of attention.

Clients notice that an attentive, susceptible way of listening is different from other ways of listening. The quality of listening is determined by notions such as rest and taking the time, and by feedback showing that you have understood what the other said.

He just has the calmness to sit back. And to listen well. And then, yes, to come up with good remarks. […] He just listens and then responds. (FJ)

On the question how a professional understands what is needed, PV answered: *Because she is listening. She is listening. And I just tell her what is happening.* (PV)

I noticed that she was listening, that she wanted to acknowledge my problem. (GK)

Sensitiveness and responsiveness

Asking questions and listening to the person seems to be embedded in and complemented by a *sensitive* and *responsive* way of communicating. The person perceives that the professional is sensitive towards his or her situation and needs. This is experienced by the way the caregiver responds to feelings and needs. This may be done by providing room for emotions or discerning own feelings or opinions.

Responsiveness is closely connected to sensitivity. It is the ability to respond to the other person on the basis of what is sensed. Here the professional actively reacts to the communication of the other.

> *You need a certain involvement, and also show at the right moments that it can go better.* (AD)

Responsiveness means being approachable and accessible, but also being complaisant and pliable (here it has a connection to moving with). The word 'answer' is related to the word 'response'. One answers to the wishes, expectations, needs and demands.

> *He knows to put that in a very flexible way, and often with a lot of humour, not too serious. But at the right moment he is sincerely concerned.* (AD)

A number of narratives make it clear that especially in the stabilisation phase, but also in reorientation, situations can be quite confusing.

> *The complicated thing of being mad is that you don't see yourself for what you are. Anger or grief, it is one big mess. […] If someone had said to me at that moment: "Gosh, it seems that you are in grief", I would have denied it out loud, because I was just fighting.* (EH)

An internal fight can be projected onto the caregiver. An important quality is seeing that someone is struggling and acknowledging this struggle.

> *I know this is complicated, but just sitting beside someone, in his despair. According to me, that's the greatest art.* (EH)

> *I have been very angry and aggressive. In psychiatry you expect people to have experience of how people can react. […] And that they understand what is happening, and still leave the responsibility for your behaviour to you.* (KP)

Responsiveness does not mean that a professional should accept and allow everything that is happening. A number of clients indicated that they appreciate what might be called a 'double response', both reacting with understanding (or trying to find out what is happening) and being clear about how they feel about it.

> KP explained it as follows: *Sometimes people should dare to be confronting. This can create clarity. At times when I was flipping, it was necessary to confront me with my behaviour. To say: "Hey, what are you doing?" […] You don't have to accept everything.* (KP)

This can also be understood as actions that help a client find and manage the boundaries of his or her personal space. By responding in acute situations to the emotions caused by the situation, such as being frightened, the personal and human side becomes visible.

Being responsive to emotional needs means for example to respond to the desire to be *comforted*.

> *I think that caregivers should be foremost comforters (smiles), good comforters. At times when I was deeply mourning, I needed this very much.* (EH)

Responsiveness can be expressed from the angle of personal experiences.

> *What I will never forget is that he said to me that from time to time he also didn't like life. That he had days that he was fed up with it. Well, that was exactly the right thing to hear.* (MR)

Clarity

By and within the dialogue it is important that things become as *clear* as possible. This refers to *making things explicit.* This clarity has two dimensions. Clarity from the side of the professionals, e.g. about their intentions, and helping clients to *express* themselves, to make themselves understood and helping them to understand themselves, their experiences and their perspectives.

Professionals have to be clear about intentions, boundaries and personal norms. They must be transparent and congruent, for example by providing insight into their

motives. For the participants in this study it was important that they experience a professional as open and transparent with regard to intentions and boundaries. This also provides a certain structure that contributes to safety and trust.

I need clearness. I need facts. (GK)

People like professionals who also state when they disagree and who don't avoid conflicts.

Basic communicational skills are needed for dialogue, both from the side of the professional and from the side of the client. From the side of the professional, language that can be clearly understood is important.

Room for expression

The caregiver helps the client to express him- or herself, to tell his or her story. The person is helped to understand and explain him- or herself. By this conversation an articulation of experiences, needs and ambitions takes place.

In a number of stories, participants indicated that what helped them a lot was that professionals helped them to express themselves.

DG had been in an isolated position, which also added to the development of his mental problems. *I talked very poorly. I could not express myself. Now I am learning.*

It is interesting to note that in the process of reorientation, many clients are helped, through the dialogue with professionals, to engage in dialogue with themselves. The professional has a feedback or a mirror function, assisting the search for meaning and identity.

She supported me to learn how to listen to my body and my feelings. (PV)

We went through a number of fairy tales. […] They are full with symbols that I recognised in my own biography. By talking about it, I got more understanding about how I have been damaged. (FJ)

HM learned through the 'good' conversations he had had with his psychiatrist and personal counsellor to have *a good conversation with himself.* He referred to a phase in his process when he 'woke up', thinking about his future perspective, and consequently making a switch from being a long-stay patient in a psychiatric hospital to a future as an individual outside psychiatry. *And then you have a good conversation with yourself. You wonder whether you want to pass your whole life in a hospital. Only walking a bit in the garden. Or do I want to get out and about, being among people, being nicely at home.* (HM)

4.2.3 Interpersonal space

The immanent and communicational notions described above constitute an interpersonal relational space. At the beginning of paragraph 4.2 I defined this as the presence of a psychological and phenomenological space in which a constructive interaction between two people can develop. This interpersonal space is characterised by safety. Within jointly created boundaries, the person feels free to *express* and reveal him- or herself.

The word 'room' or 'space' was often mentioned in the narratives:
- room for dialogue; room for emotions; room to breathe; space to move (around, again); room to be myself; room to express myself

- adequate space or opportunity for freedom of movement or action; space for experimenting, for choosing, to put things into perspective; space for permitting talents free scope

One could argue that the elements of constructive communication, such as listening attentively, asking in an enquiring way, being susceptible and sensitive and giving responsive feedback, might be sufficient for good care. But from this study it can be concluded that a connection that provides care and support in itself also contains other notions such as respect, trust and continuity. These notions lift the connection above the level of ordinary conversation or simply an exchange of information. This touches upon a relational and existential level. The combination of the immanent notions for establishing a personal connection and the notions belonging to constructive communication seems to lead to a 'caring relationship', which the participants in this study experienced as beneficial.

Within this interpersonal space, there is room for 'being'. The person can be an individual with his or her peculiarities. The word 'room' is often mentioned in the narratives, for example in the phrase "There was room for expressing myself". 'Room for expressing' is what seems to be crucial in the interaction between professional and client. A client should feel that he or she can express him- or herself and that this is confirmed by the communication from the professional. 'Room' also has a psychological dimension. Besides room for dialogue and for the expression of emotions, experiences and so on, people want to experience room to breathe and move around. Room can also be a reference to a place that feels safe and gives the opportunity to relax. Another aspect of the notion of room is that it is an adequate space or opportunity for freedom of movement or action: for experimenting, for choosing, for putting things into perspective and for permitting talents free scope. I discuss these aspects when describing the category of 'strengthening'.

Examples of creating an interpersonal space

Good care providers give room to emotions.

> *If it was going bad with me, I could just meet him […]. And I didn't have to say anything. Then I could just cry.* (FJ)

GK connected the notions of attention, conversation (dialogue) and time.

> *I think attention is important, safety in conversation. And not interrupting like that. No, finishing that conversation […] I don't like an unfinished story.* (GK)

Sometimes the right conditions for dialogue can be created, but it takes time for the client to perceive this as a niche that can be used to his or her benefit.

For GK an important turning point was when he had the experience that a nurse was really listening to him. However, he stated that if caregivers had been trying before to start a dialogue with him, he had not responded.

> *Maybe I had been listening, but I was just following my own way*. (GK)

This own way implied that he continued to behave in a mode of aggressive opposition. This behaviour was however also summoned by the behaviour of the professionals, who were fighting against him, using their power to exert the rules of the institution. After they had been trained in the CARe model, they

changed to a dialogical, responsive way of working, thereby creating conditions for a space in which connection could become possible (see Gofers, Giebels, Den Hollander & Wilken, 2002).

4.3 Understanding

In the category of understanding, I make a distinction between 'understanding the person', 'understanding the situation of the person' and 'understanding experiences'. Although the person is connected to his or her situation and experiences, I make this distinction based on the following reasons. First, this distinction came to the fore from the analysis; each part is sufficiently charged with meaningful categories. Second, it enables the separation of aspects that are related to personhood, such as personality and identity, from aspects that are related to the actual needs of the person. Third, separating 'experiences' from the other two emphasises the importance of the validation of *personal meaning* of events, which became evident from the narratives, and also enables one to put events in a time perspective and not only focus on the present situation. In Table 4.4, different elements of these three distinctions are listed.

Table 4.4: Aspects of understanding

Understanding	*Valuable elements seen from the perspective of the person*
The person	Professional understands me as a person (understands what I am like, how I am); sees me as a whole; sees who I am as a person; sees me as a person, not only as a 'case' or 'disease'; helps me to understand myself; helps me to sort out my desires and my future
The situation	Understands what my situation and my problem is; sees what the matter is; looks for what I want and need
Experiences	Professional understands my personal experiences; ,my personal experiences are (made) important; professional asks about personal experiences; helps to reflect on and learn from experiences (validation of personal experiences)

Understanding the person and his or her situation is often expressed by the words 'looking' and 'seeing'.

A good professional has to be able to observe well and to see the other. (AD)

Looking and seeing are related to being perceptive and sensitive. Participants stated that they valued that a professional 'sees the whole picture'. Apparently, understanding of just one part, for example a specific problem, is not enough. The professional has to be able to put this problem into a larger perspective. Although this larger perspective theoretically also consists of the perspective of the professional, the community and the society, in first instance the professional should understand the personal perspective of the person. For the person, his or her larger perspective is determined by his or her personal experiences. That is why he or she wants to tell about personal experiences. These experiences comprise not

only facts and events, but also the thoughts, ideas and feelings of the person about these facts and events. The subjective dimension has to be expressed and understood.

By dialoguing and having room for expression, the person perceives that the professional gains understanding of him or her and of his or her situation and personal experiences. This comprehension does not only concern the needs of the person, but also the person him- or herself and how he or she perceives his or her situation in the actual context, as well as in the context of his or her life. People value that the professional not only focuses on (understanding) the present problem, but also considers this problem in a certain context. This contextualisation is done by paying attention to experiential factors. Although the professional no doubt will have his or her own idea about the situation and expresses this as well, he or she should not present this as the 'truth' or the dominant interpretation of reality. In such a situation, there is not only room for the person to present his or her thoughts, but these thoughts are also respected. The professional connects to the subjectivity of the person, and by the way in which feedback is given, the person perceives that he or she is understood. The person experiences that the professional grasps the significance, implications or importance of what he or she wants to communicate.

Understanding has multiple levels. It entails not only rational understanding, but also emotional understanding. It is valued when professionals have understanding of the suffering and show sympathy and compassion. For the participants in this study, the understanding of their subjective experiences is as important as understanding the facts. Here, understanding obtains an empathic meaning.

> *It is important that a care worker is sympathetic, and that she looks with you at the issues you can work on. Yes, someone has to sympathise and has to have understanding for the situation.* (KP)

The act of understanding is also an act of affirmation. The person experiences that he or she as a person and his or her experiences and situation are affirmed as being valid. By this, he or she feels recognised. For further elaboration on this, see paragraph 4.4.

By the act of understanding, things can be clarified and thereby can become (more) comprehensible, containable and potentially manageable.

> *I've had so many care workers. But some are special; they just got it. […] They feel you. Yes, feeling. You get understanding. You have a problem, and they understand it!* (DG)

Understanding is associated with *familiarity*. Through understanding, a special connection is created, and since it often concerns intimate information, the professional in a way becomes related to the person as a close member of the family. In some narratives, this was intensified when the professional told about his or her personal experiences that are similar to the experiences of the person.

> *He was saying that he sometimes also has bad days. […] I felt that he could sense some of what I was enduring.* (MR)

Through this dialogue, people also experience gaining better understanding about themselves. They better understand (traumatic) events that have contributed to the current situation, and the emotional impact these had. Understanding what it is and how it works makes it easier to find a way to handle different consequences of the vulnerability. 'Telling the story' contributes to 'understanding the story'. A constructive dialogue can help to develop an explanatory framework for understanding the experience of an illness or disability. This understanding helps to put experiences in the context of the own life and biography. A better understanding of the self supports the development of the personal identity.

Understanding provides counterweight to the many times people have encountered *misunderstanding*, as is the case in the story of many of the participants in my study. It may contribute to the restoration of trust in others and in oneself. Understanding is a reciprocal notion. A professional can only understand a client if the client affirms that he or she thinks the professional understands him or her, and vice versa. Understanding should therefore be embedded in a constructive dialogue. This is clearly not the case in the next example:

> *I could not get along with the psychiatrist. He asked much too difficult questions. I just could not understand him. So if we had a conversation of half an hour, I just kept my mouth shut for half an hour.* (HM)

By mutual understanding there is agreement. Mutual understanding contributes to a state of cooperative relationship, which is the basis for the categories of securing and strengthening.

4.4 Affirming

The third category is affirming. This category is embedded in the personal connection. It has the meaning of both affirming the (being of the) person and affirming *to* the person, i.e. expressing engagement and support.

In this category I divide four notions, namely recognition, acknowledgement, affirmation and attachment. Although there is only a subtle difference between recognition and acknowledgement, I prefer to separate them. I reserve the term 'recognition' for the experience of the person that the professional *sees* or *understands* what the matter is. The person experiences that the professional *accepts* and *respects* the person and the situation as they are presented. I connect the notion of acknowledgement to the realisation of what I call the 'personal knowledge' of the person. This contains all the knowledge, experiences, talents, skills, achievements and wisdom of the person that have been gathered throughout his or her life. Through acknowledgement, the person experiences that the professional accepts this knowledge as valid and valuable. The professional *confirms* the personal knowledge of the person.

Affirmation can be seen as an act of confirmation and engagement. Not only is the person *understood* and his or her personal knowledge acknowledged as *valid*, but it is also affirmed

that he or she and this knowledge are *valuable*.[27] Recognition, acknowledgement and affirmation can also be regarded as empowering experiences. The person is confirmed as a unique individual with his or her own identity. He or she is also given *authority*, which reinforces the sense of agency.

Attachment entails the affirmation of the connection between the person and the professional. This connection is based on recognition and acknowledgement. This attachment fulfils a number of needs, such as social belonging and security, and provides a basis for (further) recovery.

In the following table the different elements appearing in the narratives are listed.

Table 4.5: Themes in the category of affirming

Affirming (to) the person (within the personal connection)	*Valuable elements seen from the perspective of the person*
Recognition	Recognition of my suffering, my needs and desires; recognition of my personhood, my experiences, talents and achievements; I feel that I am taken seriously (as a person, the problem or need, taken to the full)
Acknowledgement	The professional acknowledges (the value of) my personal knowledge: my experiences, talents, skills, achievements and knowledge (valuation and validation); I acknowledge the personal and professional knowledge of the professional (as resources for myself): his or her experience, knowledge, skills and wisdom
Affirmation	Professional affirms that I am worthwhile, that I can do it; that what I say and do is valuable; I am being honoured and empowered as a person (valuation and reinforcement); the professional affirms that he or she wants to be there for me, to help and support me; I affirm that I want *this* professional to support me
Attachment	I experience a connection, which provides personal support, social interaction, security/structure, a sense of belonging and confidence

The experience of affirmation is perceived as beneficial both on an existential level and on the level of needs. The recognition that one is (still) a worthwhile human being, an individual with a personal identity, is fundamental, both for 'grounding' the relationship with the professional and for the recovery process itself. Another aspect is the acknowledgement of

[27] I use the notion of recognition here in a phenomenological sense. In the next chapter I place the notion of recognition in a broader philosophical and existential framework, using the work of Taylor (1989) and Honneth (1995).

personal qualities, such as talents, skills and performances. Associated with this is the (growing) belief that the person and his or her life are meaningful, and that there is a future perspective. Below, the notions of recognition, acknowledgement, affirmation and attachment as they came to the fore from the narratives are described in more detail. In Chapter 5, I place them in the framework of a discourse on good care.

Forms of affirmation

Recognition implies that problems and needs are perceived and noticed. It is closely connected to understanding. Needs are connected to the larger context of subjective experiences, such as suffering and meaning. Recognition entails finding the *essence* of matters.

> KP had attempted suicide to express that he did not want 'to be put away' in a long-stay ward. After this episode, the professionals performed an evaluation to determine why this had happened. *They know that I have had a very tough time, but then they actually looked at me very well, wondering what I really wanted.* (KP)
> In this sentence it is interesting to note that there is knowledge (acknowledgement of the problems, of the suffering) and observing, trying to 'see' what KP's real wish was.
>
> In the story of AD, it had taken professionals a long time to discover the nature of his disorder. After a number of different diagnoses, finally there was a psychiatrist who 'saw what the problem actually was'.
> *I am very satisfied with the psychiatrist I have right now. He is the one who has grasped […] my real problems. So with him I felt really recognised.* (AD)
>
> Something was discovered and exposed, making it *visible*.

By expressing what is perceived and receiving affirmation from the client, a connection is made. Then there is two-way traffic: The care worker sees what the matter is and the client recognises and admits this. Or, the other way round: The client shows him- or herself and the care worker sees what is being shown.

There is also recognition in the other direction: The person recognises the experience, knowledge, skills and wisdom of the professional, and sees these as potential resources for him- or herself.

Recognition is a form of affirmation. In the narratives different forms of recognition became apparent, such as recognition of suffering, vulnerability, a problem, the client as a person, qualities and possibilities. Recognition is affiliated to 'sight' – the ability to see, to perceive something.

Furthermore, recognition is also closely related to *acknowledgement*. The act of acknowledging is the affirmation of 'knowing' what is going on. In the word acknowledgement, the word knowledge appears. An important aspect is to recognise the personal knowledge of the person, to appreciate and validate his or her experiences and the knowledge he or she has, for example about his or her disability or about the effects of certain medication. Here there is a relation to the category of 'experience'. Acknowledgement is an important aspect of the process of reminiscence or life review.

One of the processes within recovery that I have described in Chapter 3 is the 'recovery of the self' or the process of personal (re)integration. Within this process, the person looks for, becomes aware of and develops more knowledge of personal assets (such as experiences, knowledge, skills, talents and aspirations). Besides self-acknowledgement the acknowledgement or the confirmation of others is also an important support factor in this process.

Another type of acknowledgement is the acknowledgement of the vulnerable side. This is the process of adaptation to impairments. In this process, gaining personal knowledge is important. Besides self-acknowledgement, here too the acknowledgement or the support of others like professionals is an important factor. From the narratives it became evident that the acknowledgement and appreciation of the way people handle their vulnerability is valued. Acknowledging the task of managing the personal space provides recognition of the disability and affirms the efforts the person has to make to remain in control.

> *I have a lot of self-knowledge now. So I know what I can and what I can't do, and I dare to act upon this. In the past I [...] often said yes to something I actually could not do. And now I know what my back land is, because if I say yes, I go home and I feel very unhappy. Nowadays I dare to say: "It is too heavy for me, I can't do it".* (AD)

Affirmation is another essential element of good care. I have placed acknowledgement, attachment, appreciation and validation within the category of affirmation. Affirmation is the act of affirming. It is the assertion that someone or something exists or is true. Affirmation, in one form or another, gives support. Or, in other words, good care is affirmative care.

Affirmation literally means 'to make firm', which suggests making more solid or stronger. Making firm also implicates security and safety. Affirmation makes a person stronger.

In the study it became evident that acts of affirmation lead to many positive effects.

> *At a certain moment, she said to me: "Actually you don't need me anymore". I said: "I still need you very much, for the indispensable affirmation. […]) You may think I am ready, but I think I should indicate when I am ready, and then I can let go". […] She agreed.* (EH)

Attachment refers to experiencing a connection that provides all kinds of benefits, including personal support, social interaction, security/structure and a sense of belonging. To attach to the professional means that a client has confidence. He or she trusts the professional enough to put faith in him or her.

> *When I was depressed I called J, and he said: "I know you can do it". I was very unsure, and I had the feeling that I could not do it. And J just said to me: "You can do it", and I believed him.* (MR)

Attachment is a reciprocal notion – the professional also commits him- or herself to the client.

Attachment can also be experienced as *re*attachment. When the person experiences alienation from him- or herself and the world, experiences of reattachment can help him or her in the process of reintegration.

Through his or her engagement, the professional becomes a part of (attached to) the social network of the client. Some clients have very small or fragile social networks, and find themselves in socially isolated positions. The professional is a welcome addition to this network. Although their role is not the same as that of others in the network, clients often see professionals with whom they have a good relationship as a kind of friend.

4.5 Securing

A fourth category is securing. In this category all the elements are included that are perceived by the person as contributing to safety and self-confidence.
Within this category, the notion of the personal niche comes forward, as described in paragraph 3.10. Another notion contributing to security is reassurance. The third notion is

companionship or togetherness. In the next table the elements of securing as appearing in the narratives are listed.

Table 4.6: Themes in the category of securing

Securing	*Valuable elements seen from the perspective of the person*
Support to take care of the personal niche	The care worker knows my vulnerability very well; he provides safety; is a guard; I feel safe to be myself; helps me to feel safe and to increase safety; provides me with a time structure; professional is precise/secure (reliable). A specific form is 'watchmanship': the care worker watches over me and protects me
Reassurance	The care worker reassures me that nothing bad is going to happen, that things will go better; this leads to relaxation, relieves tension, gives a feeling of safety, gives me confidence
Companionship	The care worker is near and shares my feelings of insecurity or my suffering, this helps me to get through a difficult phase; the care worker stays close to me, making me feel safe; I don't feel alone; He helps me to connect to other people (intermediary in social relations)

The notion of attachment from the category of affirming (paragraph 4.4) is in another form reappearing in the context of securing. Here it is conceived as the support perceived by the person from the professional with regard to safety. The professional is perceived as someone to hold on to. The professional can be regarded as someone who is watching over the person, who protects the person and who offers him or her reassurance. He accompanies the person in his or her task to maintain the personal niche and helps him or her to become more self-assured.

Support to take care of the personal niche

One specific notion that came to the fore from this study is the notion of the personal niche (paragraph 3.6). I have described this primarily as the physical and psychological space associated with vulnerability. This vulnerability also has physical aspects, such as the energy level and side effects of medication, and social aspects, such as sensitivity to group interactions. Taking good care of the personal niche is offering security.

Elements of this security are the following:
- Being aware of a 'safety zone', a certain physical and psychological space that is safe
- Active management of vulnerability to stress factors
- Perception of an integrated sense of self, in which the sensitivity for certain stress factors is an incorporated part

This security has to be ascertained internally, but others, such as professionals, can play a supportive role.

For the person, the personal niche is a 'holding environment', an environment that contains the qualities necessary for holding the person together. Professionals can play an important role in this process, by helping to explore, become aware of and learn how to take care of the personal niche.

For the professional it is important to get to know the personal niche, not only since this is important for the client, but also because the professional has to find a fitting link to the personal niche, both in terms of his or her relationship with the client and in terms of responding adequately to the needs associated with the management of the personal niche.

A professional needs to know what the niche looks like, what the boundaries are (or the lack of boundaries), how someone tries to exert control and which strengths the person is using for this. It includes trying to understand the struggle and the energy this costs. To gain better understanding, it may help to know something about someone's history. A narrative approach, as I have used in this study, seems to be a good way of exploring the personal niche.

In the starting phase of the relationship, when establishing a connection (paragraph 4.2), it is important for professionals to be aware of the existence of the personal niche. A person should be approached carefully, in order to prevent the personal niche from being invaded. A professional has to choose a proper distance to the client, both psychologically and emotionally, and sometimes even physically. It is essential to understand that the personal niche of the other *cannot* be shared. It is per definition an exclusive space. Professionals and others have to stay 'outside'.

People also associate respect and carefulness with respect for their boundaries. If they experience that professionals are prudent, this will increase the trust. Also in this respect, the presence approach offers a good starting point. As mentioned already, what certainly should not happen is that the personal space is taken over, thereby damaging the niche. Professionals should work here in what Baart calls an "abstaining mode" (Baart & Van Heijst, 2003, p. 5). This respect can sometimes lead to a paradox. Sometimes, someone can be helped by being left alone. Professionals have to respect that clients sometimes need solitude, the space to rest. This should not be confused with leaving someone alone.

From the study it became evident that it is perceived as a valuable asset of professionals if they emanate a certain sense of rest and tranquillity. This provides a counterweight in situations in which a client is restless and nervous, and has difficulty understanding a situation. The tranquillity of the professional is reassuring and forms something to hold on. It is a support in itself (this category is related to affirmation). Reassuring literally means that there is an assurance that balance will be restored. In the light of recovery, one might consider the notion of reassurance as helping the other to regain self-assurance. In this process there is a dependence on the assistance of others to provide security until the person has reached sufficient self-assurance.

In the category of connecting, one of the notions is companionship (or togetherness). It was also noted that feeling equal can also be experienced as a kind of companionship (paragraph 4.2). In the category of securing, companionship contributes to safety. When the

person knows that someone else is familiar with his or her personal niche, it signifies that he or she is not on his or her own. This familiarity makes the professional a companion, someone to accompany the client and support him or her whenever necessary. Companionship may also mean to accompany the person to help him or her connect in a safe way to other people and environments.

Supporting the personal niche

As a professional, it is equally important to remain in the own space. It may be possible that clients, who are still looking for their boundaries, take the space of the professional as theirs. By expressing own boundaries, the client is provided with a clear hold.

> This was for example the case in the situation of GK, who asked for unlimited attention all the time, not knowing where to stop. *I wanted to speak to someone the whole day long, everybody.* The care workers had to make an arrangement to put the time within certain boundaries. From the perspective of the notion of personal niche, GK did not yet have a border between his own space and that of others. By structuring time -having time for individual conversation available, but only at certain periods during the day- a contribution was made for the creation of a 'personal niche'.

People value a professional's help to find and define their niche and to define their boundaries. A professional can also assist in determining the features of 'border control', and in developing skills that are useful for taking care of the personal niche. Aids can also be provided, such as medication. Medication management is part of taking care of the personal niche, but then in the sense that the medication is managed by the person him- or herself.

> At a certain moment in the story of GK, he had been able to manage his medication. He states: *At D I always had to ask for the medication, but now I have them with me. I can choose and do what I want. I think that's very important.* (GK)

> In RL's life, at some moment he had needed professionals to slow him down. *I tend to bite off more than I can chew. I have always been putting high demands on myself. I was raised like that, and that's also my character. That is in my head. And then you overrun yourself. And the caregivers put a brake on me. They were saying: "You don't have to do that much […]"*. (RL)

Professionals can help to arrange the personal niche. They can also play a supportive role in the actual management, for example to point the client to a certain early warning sign or to be assigned certain preventive actions in response to a warning sign (see the role of 'watcher' in the next paragraph).

> *A number of small things can together become pretty big. Before you know, you are as depressed as a canary. I know this from myself, so I am not letting it go this far. […] Then I phone my psychiatrist or my nurse. […] Well, then we talk for a while over the phone, and then it is all right again.* (HM)

Participants mentioned a number of different therapeutic interventions that had helped them, besides medication. These interventions include cognitive behaviour therapy (Garety *et al.,* 2008; Rollinson *et al*., 2007), skills training according to the method of Liberman (Liberman *et al*., 1986; 1993; 1998) and setting up and using an early warning-sign plan (Birchwood, Spencer & McGovern, 2000). In many cases a combination of interventions was used.

The cognitive skills and the Liberman module, those helped me a lot, especially the Liberman. To solve my own things and handle stress myself. We drafted an action plan together with the nurse, to see what you can do when you hear voices … (KP)

An early warning-sign plan helped me very much. So if I saw these things on paper, I knew what to do, and of course my husband also knew what he should do. (MR)

I got a year of psychotherapy. Every week I told exactly what had bothered me the whole week. I had to make lists with points: when I had laughed or had been depressed. It was a system, with graphs. This helped me a lot; it helped me very, very much. (GK)

Watchmanship

Many clients assign the role of watcher to a professional, usually within a long-lasting relationship.

An example of the role of professionals as watcher comes from the story of DG. For him it was important that he was supported in his vulnerability with regard to the use of alcohol and the management of his medication. Although he was able to manage his medication on his own, he wanted his care workers to exert a control function. He had two care workers who fulfilled this role. He said: *I have known them for five years now […]. They are still watching me. […] It is important that they keep watching me, because there is always a risk.*

When necessary, a watcher has to switch to an active mode. He or she has to act when boundaries are crossed and the person no longer has control over him- or herself and his or her situation.

It is important that initiatives during my illness are taken by the right person and at the right moment. (SW)

After one and a half year I had a relapse. I was not taking care of myself, my house. And then there was a period that I did not leave my bed in the morning. […] My helper came every week. I must say that she was very loyal. She saw that it was going the wrong way. […] I persevered for one month. Then she said: "Now it is enough. You neglect yourself, you are not eating. You won't hold on". And then I got myself readmitted. (HM)

Reassurance

The following examples demonstrate how professionals create a reassuring effect.

She [case manager JPW] *gives me rest. I need rest. […] She has a way of behaving, this charisma. […] She is in control. In a friendly way she tells me what to do. […] This is the support I need.* (DG)

Yes, just creating a home-like feeling. So that you feel at ease. That was very nice. A quiet emanation. (KP)

PV suffered from great anxiety. In order to stabilise, he needed *reassurance, endless attention, over and over again, every hour of the day. Reassurance that nothing bad will happen.* (PV)

Reassurance is also connected to gaining some kind of confidence that the professional understands what the person is struggling with.

In the beginning I had difficulty making it understood that I needed constant reassurance that nothing bad was going to happen. […] And just information about what it is to be overwrought. […] I did not know anything about it. You need to know that not everybody becomes psychotic automatically, or schizophrenic or whatever. And that you

don't automatically end up in a straightjacket or an isolation cell. Or become insane, studying chess problems for the rest of your life. […] It was my big apparition. This seemed worse than dying. […] I was not able to make myself clear, because I was far gone. But eventually, by talking about it every day, they were getting it, and understood what it was about. (PV)

Tranquillity is associated with stability. The unbalance of the client is rebalanced by the stability of the professional. This supposes that a basic quality of the professional is to be personally stable and to have peace of mind.

JPW: What do you feel is important in her approach?
DG: She is very soothing. Just the rest. By myself I am very up, up. Now I am a bit more quite. She gives me rest. I need rest. (DG)

To 'set at rest' also means to reassure. Clients consider a relaxed way of working as beneficial to their own relaxation. In the stories things were mentioned such as having a relaxed attitude, talking in a reassuring way, sitting comfortably, taking the time and using humour. The professional may function as a role model to show how one can relax.

A relaxed way of working also expresses hope and confidence. It includes a positive message: The world is not collapsing; it will be all right; I am here for you.

I was afraid to be sent back. But there was this one nurse whom I trusted. He had something quiet about him, which made me trust him a lot. He had something fatherly, some wisdom of life. So they had a very important function for me. (AD)

Safety is associated with stability.

For GK, rest is important for his own stability. He related this strongly to safety. Professionals were part of his support system, assuring his safety. *I can lie quietly in bed, get up and then I think by myself: I am safe! That's so important: safety! […] Safety is that they are always in the neighbourhood.* (GK)

EH mentions three things she needed for stabilisation: *safety, warmth and congruent people around me.* (EH)

It is appreciated when professionals continue to address the other as an autonomous individual who has his or her own responsibilities and is capable of doing things, despite the disability. In some recovery stories, a turning point is evident when professionals shift the emphasis from taking care of a lot of things for the client (mainly in the stabilisation phase) to letting the client taking care of him- or herself (more). Responsibility is placed in the hands of the person.

We see this for instance in the story of KP: *Over the course of time they put more and more into my own hands, which I found pleasant. And I noticed that it went better all the time.* (KP)

4.6 Strengthening

Becoming more self-assured is one of the elements of the last category, the category of strengthening. Three types of strengthening can be distinguished: strengthening the identity, strengthening abilities, and the reinforcement of the connections between the person and his or her environment. All these contribute to a sense of agency or autonomy. In this process, two modes of working came forward. One is the act of learning from personal experiences; the other is the professional's positive, encouraging, future-oriented mode of

working. In Table 4.7, the elements of strengthening are listed, followed by a section providing more explanation and examples.

Table 4.7: Themes in the category of strengthening

Strengthening	*Valuable elements seen from the perspective of the person*
Identity	The care worker helps me to discover who I really am; to regain what was lost; to develop more self-confidence; the caregiver helps me to put my past experiences into an understandable perspective
Abilities contributing to a sense of agency and autonomy	My caregiver helps me to become stronger, to recover, to learn; tempts me into going shopping again; helps me to overcome my anxiety; places me more and more in charge of my own life; by the support of the care worker I get more confidence and independence/autonomy
Learning process: Learning from experiences	The professional supports me to learn (about myself, to listen to my feelings, to understand my vulnerability, to express myself, to improve social skills); helps me to understand and to develop myself (contribution to development and empowerment)
Empowering focus: Motivation, inspiration. encouragement, perspective	My caregiver provides me with support to become stronger by emphasising my talents and achievements, by giving me compliments; the professional is positive: with regard to possibilities, my qualities, achievements, the healthy side; believes that my situation will and can get better; believes in my strengths and possibilities; focuses on progression; the professional motivates me; gives me inspiration and encouragement; provides hope; sets a good example; motivates me; gives me good ideas; shows me how to do it; gives motivation to go on; the caregiver helps me to create a future perspective; helps me to choose goals; provides hope and meaning; helps me to keep the focus on my (possibilities for) recovery and development
Connection with environment	The professional helps me to establish or improve my relationship with other people; to find a job; to get an education

Identity

An important dimension of the recovery process is the reconstruction of the identity, or 'the Self'. A number of participants in the study used professional psychotherapy to go through a process of life review or rehistorisation in order to find their own identity or their sense of self.

> *And then I had 1½ years of day treatment. This was very helpful. Actually, then I could very slowly look back, to see all the things that had actually happened.* (EH)

The person reviews what has happened to him or her and finds explanations, thereby developing an explanatory framework, a framework in which the identity can be located.

> *Yes, we have been spitting through my life, to find out how it came that I have been so damaged very much. (…) Now I have much more understanding of my self and my situation.* (FJ)

In this process reappropriation takes place. The person becomes the owner of the identity. The alienation caused by the mental illness and/or by social exclusion is reduced to a level at which the person knows to separate the own self from experiences caused by the disease or by the effects of hospitalisation.

> *The last months I have the feeling that real contact with myself is being established.* (PV)

Different aspects of the personal identity are integrated into a new conception. This conception helps to handle the vulnerability better, to remain within 'safe borders'. External reintegration means setting actual steps in different domains of life. Here a new type of transition comes to the fore: moving towards society and taking up valued roles. This again increases self-confidence.

Professionals offer a safe framework in which to work on the identity. It seems to be important that they be good listeners and allow the person space to tell about his or her experiences.

> *What helped me a lot was that I could tell my story. And that they took the time for it.* (NS)

Professionals that featured in the narratives seemed to use different 'techniques' to help the participants gain understanding of themselves in the context of their life. These are the techniques described under 'constructive dialogue' in paragraph 4.2: listening attentively, asking clarifying or deepening questions and reflecting on the story. Some psychotherapists use imagination techniques, physical techniques and metaphors.

Abilities and autonomy

By working on the identity, at the same time abilities are (re)discovered and autonomy is strengthened. These competences may lay in different domains, such as handling the vulnerability and taking care of the personal niche, taking care of the household or taking care of social relations and competences related to a specific activity or job.

> *I started preparing meals here at R.* [rehabilitation centre JPW]*, together with a pall, for a large group of people, usually around 15 persons. I started to be on firmer grounds. I liked to choose recipes, and sometimes it was exciting, because were they going to like it? But at a certain moment you discover that you got the hang of it. So I really felt: I do something useful.* (AD)

Often, professionals working in social niches such as rehabilitation centres provide opportunities and support for (re)using and developing competences.

I am doing some voluntary work [at the rehabilitation centre JPW]. There I can work independently, and if I have a question I talk about it. […] Yes, I like to come there. It is a good place, a support. (RL)

At the visitors council I have become the chairman. They also asked me to be on the central client council. I am the mentor of a staff member. I am a guide to show people around. Well, I am doing many useful things. (AD)

I needed to develop some kind of firmness. R [a rehabilitation centre JPW] offered me the possibility to practice, to grow […]. (PV)

Learning from experiences

A recovery process can be characterised as a learning process. The word 'experience' was used often in the narratives. People learn from past experiences in order to gain understanding of what has happened to them and about themselves in the process of developing their identity. People also learn from present experiences. Learning takes place by collecting knowledge, experimenting, and reflecting on them.

I have just a lot of self knowledge now. So I know what I am able and not able of. (AD)

Good professionals are those who facilitate this learning process. It seems important that they understand that people learn in different ways and that they provide the right opportunities for learning.

I learned from him [social psychiatric nurse JPW] that men and women react differently. […] So I learned to speak up for myself. (MR)

You have to love yourself again, get self-confidence […]. All those talks with H helped me to rediscover myself, to build my self-belief. (MR)

He supported me to go to school again […]. Sometimes I had a bad day. […] He said to me: "I think this is a good experience, because you are saying to me that next time you are going to handle this differently. So this is also something you've been learning from". (MR)

Psychotherapy, social niches and counselling were methods used by many participants in this study to learn about themselves, to learn from past experiences and to learn how to take care of vulnerability.

At a certain moment you discover what fits you, and you also have to accept that some things are not achievable. (RL)

Empowering focus

From a majority of the narratives it appears that a positive focus is an important form of support. The participants stated that they value a professional who is serious, yet positive about chances and opportunities. Positivity can also be radiated by the use of humour.

Empowering acts provide motivation, encouragement and inspiration. Participants talked about different forms of encouragement, such as emphasising strengths and talents, rewarding achievements and giving compliments.

He gave me nothing but compliments. He was saying: "You also have qualities, real qualities, you know". (MR)

Then he came in […] and looked around saying, "Oh, what a neat place. You really did well". (MR)

Participants placed value on professionals also looking at the healthy side. When he or she believes that the situation will and can get better there is focus on progression. This is associated with the notion of hope.

The professionals who featured in the narratives also gave inspiration by being or showing good examples, either from their own life or from that of other people. They were also creative and came up with good ideas. In 'bad times', professionals can be a beacon of hope.

> *If I was depressed I gave him a call, and then he said: "I know you can do it!"* (MR)

Finally, caregivers can help to create a future perspective. They can help to choose desired directions and develop goals.

Good professionals keep the focus on (possibilities for) recovery and development. However, they do not go 'over the edge'. They respect the pace and the own initiatives of the other. In a number of narratives, the professionals remained present for a long period with people who seemed to remain in a bad state. They did not give up, and waited patiently until the person gave a positive response, which is often retrospectively considered a turning point for which they were grateful.

Connection with the environment

A last category of strengthening is the support of professionals to establish or improve the relationship with social environments. Hereby they contribute to maintaining bonds during times of hospitalisation and to social reintegration.

During treatment in the stabilisation phases of the recovery process, people value that professionals involve close family members. Reasons for this are the following:

* Family members can help to explain the situation to the professional
* Professionals can help to explain the nature of the disease or disability to relatives in order to increase understanding and support
* Professionals can help to overcome the stigma associated with the disease

> *They had a lot of talks with my family, especially with my father. They ensured that my father got a better understanding of my situation*. (KP)

> *He explained very well to S [husband JPW] what it meant to have experienced a psychosis so many times, and that this has consequences. So then he was more understanding and had more consideration.* (MR)

> *She [social-psychiatric nurse JPW] came home to my mother's place. We had talks, the three of us. To speak about what was happening with me, about the medication, and what the future was going to look like. […] I liked it very much that they were involved, my parents too.* (KP)

In the reorientation phase, professionals refer clients to recovery training sessions, self-help groups or other forms of peer support, such as social niches created by mental health agencies or consumer-run organisations. From the narratives it can be concluded that all these forms of support are very useful.

> *I took the step to go to the day activity centre. Well, I felt a small part of a kind of social community. That feeling was very important to me.* (AD)

> *And also by meeting other clients, to hear other stories, I didn't feel so alone.* (EH)

In the reorientation and reintegration phase, professionals help to (re)connect people to their natural social network, e.g. their family, the environment in which they live, or environments in the domains of education, work and leisure.

> *I had a very good relationship with my psychiatrist. Also because he involved my sons […] to support me to get back home.* (HM)
>
> *She said to me that I should develop myself, that I should take some steps. […] So I started looking for options, and worked in a bicycle-repair shop.* (HM)

When I was home again, I was so anxious that I did not dare to go shopping. […] So he [social worker JPW] *went with me to the grocery store, and after a couple of times I could do it on my own.* (HM

4.7 Relationship between categories

From this study, five categories of good care emerge: connecting, understanding, affirming, securing and strengthening. The question is what the relationship is between the categories.

If one analyses the different elements of the categories, a number of them do not exclusively belong to one category. For example, establishing a personal connection is also accomplished by elements belonging to understanding and affirming. If a person feels that he or she is approached in a respectful way, he or she often expresses that he feels recognised. Some notions have slightly different meanings in one or another category.

I used a number of theoretic ways to understand the relationship between categories. Firstly, I constructed a model that follows lines of external logic. I looked at a formal structure. Secondly, I followed the lines of an internal logic. I looked at the categories from the perspective of the neediness of the person. Thirdly, I followed a dynamic line of reasoning, looking at the categories from the perspective of process and time.

4.7.1 External logic

The first way in which I looked at the categories was from the perspective of the neediness of the person. I assume that the basis for contact between a person and a professional caregiver is a supposed need for help or assistance. This is therefore a specific type of neediness, which is different from the general human neediness for support by natural network members. When the categories are considered from this perspective, a number of 'hidden' interests can be recognised from the narratives. In the background of the stories are a number of elements to which professionals are (or have to be) implicitly or explicitly responsive.

This perspective could be grasped in terms of seven questions, which can be divided into three clusters, as depicted in Table 4.8. People look at signals or messages to test the professional and to find answers to these questions.

I divided the questions into three clusters because there seems to be a chronologic order. The first cluster contains questions that should be answered first. They concern establishing a primary connection. The questions can also be summarised as a need for confidence. The second cluster concerns responding to the needs connected to burden or suffering. These questions can also be regarded as a depiction of the need for competence. The third cluster comes under consideration when a basic personal connection has been established and the most urgent burden has been relieved. These questions concern the search for identity. They are connected to the desire for the recovery of a positive focus or a desired future perspective.

Table 4.8: Clusters and questions providing external logic

First cluster
1. Who are you? Can you be trusted?
2. Are you someone with whom I can feel safe?
3. Are you someone who really understands me?
4. Do you acknowledge and reaffirm me?
Second cluster
5. Are you able to relieve me / help me to relieve myself?
Third cluster
6. Do you help me to see who I really am?
7. Do you help me to create a perspective?

The first question is a basic question that is fundamental to each social contact. However, for extremely vulnerable people, who had often encountered a lot of mistrust in their lives, it is very important that they determine whether the professional is a person who is honest and has integrity. Clients are fundamentally uncertain in their vulnerability, and are constantly looking for balance. They not only want someone who understands them, but also to have the vulnerability affirmed[28]. This affirmation is not only an affirmation in the sense of understanding, but also an affirmation in the sense of securing. A form of attachment with the professional provides an anchor point, something (someone) to hold on to, which contributes to safety and maintaining balance. Many people say that they acquire trust in the professional because the professional remains with them, does not leave them despite problems and/or does things for them that reduce the stress they experience.

Question 5 has two components: an appeal to the professional to do what the person is not able to do him- or herself, and an appeal to help him or her overcome his problems him- or herself. It is clear that both appeals are not always present, or are not always present at the same time. In some stories, like the story of HM, the emphasis remains on the first type of appeal for years, as he required professionals to help him while he did not undertake any action himself. At a certain moment in time, a turning point was visible, shifting the emphasis gradually to a situation in which he himself wanted to become stronger and lead a more autonomous life and asked professionals to support him with that. The turning point is characterised by elements from the first cluster: He started to trust caregivers and they acknowledged his talents and encouraged his possibilities.

It seems that confirmative answers to the first and second cluster form the basic conditions for the third cluster. The third cluster contains two questions: “Do you help me to see who I really am?” and “Do you help me to create a perspective?”

[28] From a phenomenological point of view one could also rephrase question three in this cluster as: “do you really see in which space you find yourself?” It is an appeal to connect to the life world and existentiality of the other.

I have placed these questions in a separate cluster, because from the narratives it becomes clear that these tacit desires come to the surface only after the first five questions are answered affirmatively. Both questions make a double appeal. The first appeal is made to the perception and understanding of the professional. The second appeal is made to the support of the professional in order to help the person.

"Do you help me to see who I really am?" is accompanied by the question: "Do *you* see who I really am?" which is related to question 4. This refers to the desire for (self)affirmation. There is a shift here from external recognition towards internal recognition. This question is related to the search for *identity*, which features so prominently in many stories that reflect disrupted biographies. Behind this appeal is also the desire to reconnect to (hidden) strengths and ambitions.

The question "Do you help me to create a perspective?" is connected to the desire to develop an outline for a desired future. Behind this appeal is also the desire to become stronger. This question aspirates notions of liberation, of recovery and development, and of social participation and a meaningful life. The question places the emphasis on the professional offering some prospect of the future. In many stories this was phrased as professionals still having hope, remaining positive and so on. The question also indicates a desire for support to discover and create personal ideas and goals.

If the questions in the second and third cluster are answered affirmatively, this reinforces the connection established by affirmative answers to the first cluster of questions.

In the next table the relationship between the basic questions and the categories is listed.

Table 4.9: Basic questions and their relationship with the categories

Basic questions in the relationship between client and professional	*Related categories*	
1. Who are you? Can you be trusted?	Securing	Connecting
2. Are you someone with whom I can feel safe?	Securing	
3. Are you someone who really understands me?	Understanding	
4. Do you acknowledge and reaffirm me?	Affirming	
5. Are you able to relieve me / help me to relieve myself?	Securing; Strengthening	
6. Do you see / help me to see who I really am?	Understanding; Affirming	
7. Are you able to offer me / help me to create a perspective?	Strengthening	

A connection is established through the securing, understanding, affirming and strengthening acts of the professional, being *perceived* as such by the recipient. In the process of establishing and maintaining a personal connection, these acts form the active and constituting ingredients.

4.7.2 Internal logic

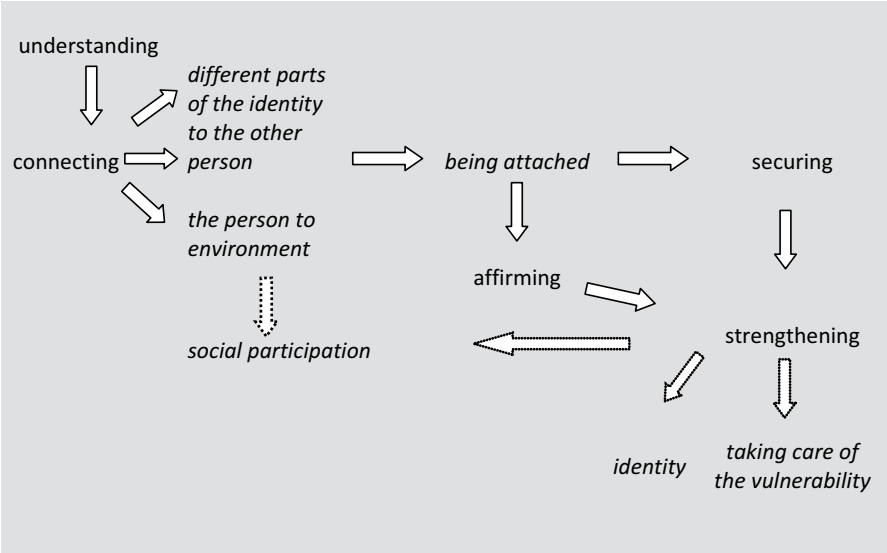
Within the category of connecting a distinction can be made between the *structure* and the *culture* of the relationship. Structural elements, which constitute the architecture of the relationship, are for instance providing safety and creating room for dialogue. Cultural

elements are for instance being respectful, creating a relaxed atmosphere and experiencing a positive focus.

Although within the category of connecting I have restricted myself to aspects of relation and communication, the relationship with other categories is also present through the *functional meaning* a personal relationship has in terms of other categories. By means of the relationship that is established, people feel affirmed, secured and strengthened. For a personal connection, understanding each other is crucial. The personal connection itself, as a form of attachment between the two parties, forms the foundation for securing and affirming. Affirmation and safety are foundations for strengthening (empowerment). The experience of being connected or attached to the person of the professional contributes to a sense of security, thereby fulfilling a need with regard to the psychological vulnerability. Being affirmed as a person, by ways of the professional understanding what is going on, contributes both to securing and to strengthening. Connecting also has the meaning of helping the person to put different elements of his or her narrative into perspective. For example, past experiences are connected to present experiences. Part of connecting from the side of the professional is to connect not only to the individual, but also to the context of the individual and his or her living environment and social network. This is necessary to gain a complete understanding of the situation of the person, but also to be able to relate to significant others in the social network of the person, others that might play an impeding or a supporting role. Finally, a meaning of connecting is to help the person to be reconnected to the world in terms of meaningful roles or activities.

In the next figure the relationships described above are depicted. The dotted arrows represent the contribution to the recovery process.

Figure 4.1: Internal logic between the categories



The result of the connecting process can be characterised by the word *attachment*. An important aspect of a recovery process is that, partly due to the attachment the professional offers, the person is helped to reattach to his or her self, to his or her biography and to the world. (Re)affirmation serves as an essential 'connecting' notion. Attachment provides security, acknowledgement and a social connection.

In the centre of the scheme I have placed the word 'being attached' as an intermediary notion. When a personal connection has been established, this means that the professional has attached him- or herself to the client and vice versa. This attachment has different meanings and expresses a commitment from both sides. It provides a double function for the client: The client can use the connection with the professional as an anchor point and as part of the fulfilment of the need of safety, and it serves as a basis for development and growth.

Through the connection a professional is able to understand the person (better), and therefore to help him or her to feel safe(r) (securing) and to develop him- or herself (strengthening), in terms of handling the vulnerability, developing identity and increasing social participation.

4.7.3 Logic from the perspective of time

A more dynamic insight is effected when the categories are considered from the process perspective of *time*. I state a number of observations.

(a) *Time* is a notion that acquires many different meanings: taking time, having time, giving time, no time pressure, timing, the right thing at the right time, *being there* for a long time and focusing on process and duration. Time is connected to the categories availability (presence), attention, continuity and perspective.

(b) Time is also associated with the notion of *room*, the room that is experienced psychologically by the person to interact in a desired way with the professional. Room is in most stories not created by the person him- or herself, but provided by the professional. Room is created by taking the time, by being attentive and having a relaxing attitude.

(c) Good *contact* between a caregiver and a care receiver is an important basis for communication and interventions. Good contact can be defined as the contact that enables professionals to engage in a relationship, to gain an understanding of the needs of the person, and to provide the needed support. It is difficult to tell exactly which elements compose 'good contact'. Good contact seems to include an affective component (I like him) and a valuing component (I think she is able to offer me something), including the feeling of confidence.

Considered from a time perspective, it seems that there are two patterns for good contact being established: the pattern in which contact starts instantly by experiencing 'a personal click', followed by the other stages, and a pattern in which at first there is resistance, which at a certain moment decreases or is turned around. The first pattern starts at the beginning, with an affective stance (it feels good; I sense a click), then there is a cognition that the professional understands what is going on (I feel he understands me). In a

later phase, good contact is maintained by an appreciative component (he is indeed a nice fellow; he has done a lot for me; he is trustworthy). Then certain affection is developed further; the intensity may be increased, leading to the development of a kind of trustful relationship, which is more intimate than confidence. Facilitating factors for establishing good contact are a respectful attitude and a relaxing way of acting, expressed by taking the time, sitting at ease, talking about ordinary things and using humour.

> In Chapter 3 there is an example of the second pattern. At first, NS had refused all contact with professionals. After a while, he started to accept contact because, as told retrospectively, he appreciated the great effort they made by showing up at his door over and over again. Here the establishing of a connection started after the appreciation of a continuous effort.

Resistance is often there in situations where the person has initially not asked for help. An impeding factor may be that the professional is associated with a system that is in turn associated with negative experiences. In other words, the professional is not seen as a *person* but as an instrument of an unwanted system. Personal contact is therefore avoided. Much depends on the intentions of the professional: whether the professional is able to communicate his or her intentions and whether the person responds to these intentions.

(d) A crucial notion is one of *appreciation*. At a certain moment in time, either directly at the beginning or after a while, the professional is perceived by the person as nice, sympathetic, understanding, trustful and supportive. This is the point at which the interaction starts to be potentially collaborative. Such a perception is a condition for the professional to receive information from the person, and to start working on problems or a desired future perspective. This leads to a form of attachment and mutual understanding.

A connection can already be established at the first meeting between the professional and the client. As said, if the professional is perceived as a nice person, this is already a good starting point. There may be different elements that lead the person to perceive the professional as 'nice'. From the narratives elements such as being relaxed, taking the time for me, being humorous, being complimentary, being sensitive and being personal appeared to be important in this regard. In addition, being professional, in the sense of being knowledgeable and showing good understanding of problems, is valued.

The development of reciprocity

The concept of reciprocity can be applied to a number of relations between categories. Connecting is in itself a reciprocal notion, because it presupposes two sides. There is a symbolical connection between the professional and the client. The reciprocity in this connection is expressed by facing each other, by shaking hands, by dialogue and by joining in the same activities. Attaching the person to him- or herself (biography, identity) implies that reciprocity is (re)established between different parts of a person's life that had drifted apart. Connecting the person to a specific environment means establishing communication between the person and other individuals, whereby reciprocal interactions are created.

Reciprocity is also present in the notion of understanding, in the sense of mutual understanding. It is not only the professional who thinks he or she understands the client, but also the client that perceives the professional as *being* understanding. For the professional it is important that in communication with the client he or she feels understood

with regard to his or her intentions and actions. The professional also needs affirmation. He or she has to feel secure in what he or she is doing for and on behalf of the client. In the narratives it is clear that people value the experience of the professional. They use this as a source for themselves. The professional provides a 'good example', hope and wisdom and functions as a source of knowledge.

From dependency to self-reliance

The process that is revealed here shows a recovery or empowerment line, in which strengthening is achieved through understanding or discovering, securing and affirming. This process can also be described as a continuum moving from dependency to self-reliance. At the beginning of the process, when professionals meet people who are struggling with their disorder, with chaos inside and around them, people often depend on the safety offered to them by professionals. The self is often disrupted because of a psychiatric disorder and/or traumatic experiences. The sense of a personal identity has become very vague, offering nothing to hold on to and causing a great loss of security. In the course of the process, the self reappears again. This takes multiple forms: the self as a personal identity and increasing self-understanding, self-confidence and self-reliance (also in the sense of self-care, i.e. being able to take care of oneself again).

4.8 Conclusion

In this chapter I searched for categories and notions in the empirical data that are associated with good care. I defined good care as: "Care that is perceived by a receiver of care as beneficial". Beneficiality can be derived from five different categories which can be considered as 'personal-professional acts'. These are the acts of connecting, understanding, affirming, securing and strengthening. It seems that the professionals who are identified as really beneficial combine a number of elements belonging to these categories. They seem to be able to establish a relationship that includes a connection on a personal level. It seems that 'personal' is not always easy to define. 'Feeling good' with someone is constituted by a number of elements, which probably have in common that a person feels 'seen' and at ease. The categories of understanding, affirming, securing and strengthening reinforce the connection and 'charge' it with meaningful behaviour – meaningful in the sense that the presence of the professional acknowledges, secures and strengthens the person. In order to feel acknowledged, secure and strengthened, a person must feel understood by the professional. Acts of recognition, securing and strengthening are preceded by or based on an expression of understanding.

Connecting can be regarded as a process that may start with a glimpse of sympathy for the professional that deepens over the course of time. Sympathy can be evoked by the empathic attention the professional has, by the respect he or she shows, or by the humour he or she uses. Connecting can also take place due to tough confrontations and a stubborn persistence.

Deepening of the relationship can develop due to reciprocity in the relationship, by dialogical conversation, a continuing presence, and by acts of commitment and dedication. The connecting process may result in a feeling of togetherness or companionship.

It is intriguing to see that in the narratives also many professionals feature who are not perceived as particularly helpful or supportive. These professionals often appear faceless or nameless; they are referred to only by their formal function or discipline. They are considered to be part of a group of caregivers that provide services on the level of a group or facility. They are not perceived as providing individualised services and seem to be interchangeable. Although these professionals, often referred to as 'ordinary professionals', do what they have to do (in a functional way), they apparently lack the quality of engaging in a personal relationship.

The relational and communicational notions that were identified create a so-called *interpersonal space*. This is a psychological and metaphorical notion that expresses a number of qualities that are needed for constructive collaboration and for supporting recovery in a beneficial way. In this safe space there is room for being, room for expression and dialogue, and room for development.

The narratives also show numerous examples that an interpersonal space does not develop or does not hold. Persons indicate that in those cases they don't feel being listened to, that they feel being treated in a paternalistic way, and that they don't experience equality and respect.

The notion of understanding is connected to the sensitivity of the professional for the personhood of the other and his or her situation and experiences. The person feels understood on the basis of the being and expressions of the professional. The professional also contributes to a better understanding by the person him- or herself. This can be done by letting the person tell his or her story, by asking clarifying questions and by helping to put experiences in a larger perspective.

A very important act that came to the fore from the analysis is affirming. This notion has a threefold meaning. The first is that the professional answers to the need of the person to be recognised as a worthwhile human being, with a personal autonomy and a unique identity. The second is that his or her personal experiences and knowledge are acknowledged (as being valid and valuable). The third meaning is that the professional expresses that he or she attaches him- or herself to the other and expresses engagement and support. The personal–professional connection is affirmed, also from the side of the client.

The attachment between professional and client provides a form of security, which answers to the need of feeling safe and of having someone to hold on to. Within the act of securing, other, more specific elements are also visible, such as assistance to take care of the personal niche and the offering of reassurance. The professional may also serve as a form of 'social insurance' by offering companionship.

One might say that securing, understanding and affirming are the basis of a supportive relationship. Although this helps the person to feel connected, to feel recognised and to feel safe, which in itself are basic human needs, this may not be enough for recovery. From the perspective of the participants in the narratives, acts of strengthening should also be added. Here the professional helps with the three fundamental tasks of recovery: reconstructing identity, increasing skills to take care of the vulnerability and restoring autonomy and social participation. Important empowering acts seem to be discovering the core identity by

learning from experiences, emphasising talents and achievements, offering inspiration and encouragement, working on a future perspective, and connecting people to environments that offer space for growth.

A connection and collaboration between professional and client seem only to be established if there is a kind of reciprocity or responsiveness from both sides. This study reveals basic conditions and elements of these notions. In the next chapter I elaborate on these insights, using relevant scientific sources to contribute to a theory and practice of good care.

Chapter 5 Contributions to a theory of good care

This and the next chapter build on the findings of the previous chapters. I am putting the elements of care as perceived by recipients (chapters 2 and 3) and the underlying notions (chapter 4) in the perspective of an emerging discourse on good care, using references from a variety of scholars. In this chapter an ethical foundation and six tenets are presented. Also the objectives of good care will be described. In the next chapter the characteristics and qualities that appear as relevant in the analysis of the narratives are explained. Then the elements constituting a practice of good care are described.

Reading tip: This and the next chapter consist of five parts that together form a discourse on good care. In this chapter you will find the *theoretical foundation* in paragraphs 5.3 and 5.4 and the *objectives* of good care in paragraph 5.5. *Characteristics* and *qualities* are described in paragraph 6.1. If you are specifically interested in implications for *practice*, you are referred to paragraph 6.2. In the boxes, background information on notions can be found. If you simply want to read the main sections, you can skip these boxes.

5.1 Introduction

In this study, good care is defined as: "Care that is perceived by a receiver of care as beneficial". This definition places the focus on the receiver and his or her perception of professional services. The angle used in this definition is subjective by nature. However, by using the data of my own experiential study and those of others around the world, and by looking for grounding notions, it becomes clear, in an objectified way, how professional care can contribute to the wellbeing of a person. It is obvious that these cornerstones only provide a basic logic, yet in each and every situation they get a particular and unique form and significance.

I have analysed what recipients of care (in this study users of mental health care) consider as contributions to their wellbeing. I have looked at underlying concepts, and was able to identify five categories, namely connecting, understanding, affirming, securing and strengthening. I also investigated the relationship between these categories.

The perspective of the recipient is the main focus of this book. I tried to determine what, from the perspective of the user of care, is perceived as helpful or supportive. Apparently, the 'good professionals' in the narratives were able to effect a connection between their perspective and that of their client. Understanding this perspective made way to connecting to the needs of the person, acting in an affirming, securing and strengthening way.

Connecting as a professional to a person on a relational level, and understanding his or her perspective (in terms of history, problems, suffering, needs and ideas about the future), seems to be crucial. In this respect, this study underlines the importance that is allocated in different psychosocial rehabilitation models to creating a good relationship or working alliance with a client (Anthony *et al*., 2002; Petry & Nuy, 1997; Petry, 2003; Rapp, 1998a; Rapp & Gosha, 2006; Wilken & Den Hollander, 1999, 2005). It also affirms the theory of

presence of Baart (2001; 2004) and the theory of ethics of human loving care as developed by Van Heijst (2005; 2008).

This study sheds more light on what users perceive to be a 'good' or successful relationship. Although narratives of professionals have not been collected (although some appear in the narratives of the participants), my hypothesis is that a good professional is not only able to understand the perspective of the user, but is also able to connect this perspective to his or her own perspective. This perspective is not only the result of a personal and professional socialisation process, but is also determined by the organisational culture and the societal context (e.g. norms and laws). He or she has to develop a 'shared perspective' way of working, which is an important condition for good care.

In this chapter these notions will be elaborated on by eliciting what has been found in my empirical research. I turn the perspective of the user to the perspective of the professional. I do this by translating the essential notions of the categories of connecting, understanding, affirming, securing and strengthening into a theoretical framework, using insights from a number of scholars in the field of social sciences, philosophy and ethics.

5.2 Analytical framework

As a professional, the caregiver takes part in a *discourse*, a certain way of observing, appreciating, speaking and assigning meaning[29]. This discourse is in a way the logic of his observing, acting and speaking, which expresses what is perceived and appreciated. Through the glasses of this discourse he expresses what is wrong, what is of value, what the meaning is of certain phenomena. The discourse is the discourse of a certain community, of a group of people who share their vision, notions and evaluations. This discourse is morally charged, for it indicates what is right and good. It is also a construction of power, because it hides points of view and puts others in sight. In the discourse on good care, which I develop below, I use a fourfold division, which serves as the 'architectural plan' for the discourse.

1. The first section starts with an *ethical foundation* (paragraph 5.3). This foundation forms the basis of six different *tenets* (paragraph 5.4). The six tenets are presence, shared perspective, diversity, recognition, autonomy and vulnerability, and empowerment. I approach these theoretical angles as tenets, because they require from professionals

[29] In the work of Michel Foucault, and social theorists inspired by him, discourse has a special meaning. It is "an entity of sequences of signs in that they are enouncements (enoncés)" (Foucault, 1969, p. 141). An enouncement (often translated as "statement") is not a unity of signs, but an abstract matter that enables signs to assign specific repeatable relations to objects, subjects and other enouncements (Ibid: 140). Thus, a discourse constitutes sequences of such relations to objects, subjects and other enouncements. A discursive formation is defined as the regularities that produce such discourses. Foucault used the concept of discursive formation in relation to his analysis of large bodies of knowledge, such as political economy and natural history (Foucault, 1970). Studies of discourse have been carried out within a variety of traditions that investigate the relations between language, structure and agency, including feminist studies, anthropology, ethnography, cultural studies, literary theory, and the history of ideas. Within these fields, the notion of "discourse" is itself subject to discourse, that is, debated on the basis of specialized knowledge. Discourse can be observed in the use of spoken, written and sign language and multimodal/multimedia forms of communication. In the social sciences (following the work of Michel Foucault), a discourse is considered to be a formalized way of thinking that can be manifested through language, a social boundary defining what can be said about a specific topic, or possible truth.

operating within the discourse on good care to actively practise the notions belonging to these tenets – not from a dogmatic stand, but as a learning process. The theories are not dogmatic by nature but rather hermeneutic and phenomenological. In each situation it is the challenge for the professional to work with these tenets in order to create again and again a practice of good care.[30] Each of the tenets has its own significance, but can, in this discourse, only be understood in relationship to each other. Furthermore, I consider these theoretical notions not as complete, but as cornerstones of a growing grounded and critical social theory, which needs to be expanded in further research. Together, the ethical foundation and the six tenets form the basic theories for the discourse on good care. This offers a first, theoretical answer to the question "What is good care?"

2. The discourse on good care has a number of *objectives* (paragraph 5.5). These objectives concern the ultimate aims of good care, seen from the perspective of the recipient, the profession and the community/society. Herewith an answer is given to the question "What are the (ultimate) aims of good care?"

I systematically flesh out these four parts, but before doing this, I would like to make the following remarks:

(a) The elaboration arranges what has been found empirically, so the significance which is dominant, valid and shared according to the narratives. I searched for the way in which the reality (of professional care for people with a psychosocial vulnerability) is conceived. Evidently, this is a normative activity: I weighed the statements of the participants and organised the results against my own normative background (theories of presence, care ethics, rehabilitation and recovery).

(b) The elaboration also includes situating the findings in relevant (ethic of care) literature, whereby a theoretical interpretation of the results is effected.

(c) The two notes above have as a consequence that theoretically speaking all other kinds of possible notions that could be connected to the professional discourse do not feature, simply because what has not been spoken about in the narratives does not appear in these classifications.

(d) The results are static in as far as they indicate patterns and classifications (descriptive), but they are also dynamic in as far as they describe and intent developments (intentional), and in as far as they are dependent on a continuously changing context and culture (contingent).

3. In the discourse, certain relevant *characteristics* become visible, which are apparently relevant to good care (paragraph 6.1). These are characteristics of both the care receiver and the caregiver. The professional chooses, within the theoretical framework of the discourse, a *position* or *role*. This comes with certain responsibilities the professional assumes and with meanings that are attached to different roles. The position of the professional in the discourse determines the nature of the relations in which he or she engages. Finally, a

[30] I follow here the definition of Alasdair MacIntyre (1985, p. 187), who defines practice as a form of socially established cooperative human activity "through which goods internal to that form of activity are realised in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity […]". In this view, practice is not a generalised concept. Each practice is defined by the cooperation of those involved in the practice. In every situation, over and over again, a professional has to constitute the practice, trying to achieve 'excellence'.

number of *qualities* of the professional also come forward in terms of dispositions, virtues and abilities. This section offers a second, typological answer to the question "What is good care?"

4. This position or role also comes with corresponding acts, methods and approaches, which form an instrumental translation of the tenets and the characteristics. The professional does not function in an unsettled discourse, but in a professional *practice*. The elements of this practice emerging from this study are described (paragraph 6.2). Two overarching concepts are presented. The first is the *interpersonal space*, a relational niche that forms the basis for beneficial support and help. The different notions that help constitute this space are described. The second is the notion of *care responsiveness*, which helps the professional to tune into the perspective of the recipient. The practice is constituted by eight phases. Together, they form a 'methodology' of good care. This section offers a third, operational answer to the question "What is good care?"

Table 5.1 below offers an overview of the framework presented above. This also forms the architectural plan for this chapter.

Table 5.1 Overview of elements of a discourse on good care

1. Ethical foundation and tenets	
1.1 Ethical foundation	*The ethical foundation of good care*
1.2 Tenets	*The tenet of presence* *The tenet of shared perspective* *The tenet of diversity* *The tenet of recognition* *The tenet of autonomy and vulnerability* *The tenet of empowerment*
2. Objectives	
2.1 The care receiver	*The ultimate aims of good care, seen from the perspective of care recipients* *Goods realised in the practice* *Goods realised by (as a result of) the practice*
2.2 The profession	*The ultimate aims of good care, seen from the perspective of care providers* *Social* *Physical and psychological* *Existential*
2.3 The society	*The ultimate aims of good care, seen from the perspective of society* *Social-political*

3. Characteristics	
3.1 Characteristics of care receiver and caregiver	Care receiver: *- Different (not crazy, not excluded)* *- Vulnerable yet of value* *- Has strengths (not only weaknesses), is able to contribute to personal wellbeing and the wellbeing of others* Caregiver: *- Human and competent, moral professional* *- As vulnerable as the care receiver, basically not different*
3.2 Characteristics of the (professional) position	*Change of perspective with preservation of position* *Role and identity that are chosen by a good professional (belonging to good care)* *The responsibilities accepted or taken by the good professional (belonging to good care)* *The nature of the relations (belonging to good care) in which the good professional engages and which he or she maintains*
3.3 Qualities of the professional	*Virtues of the good professional in the right position* *Dispositions of the good professional in the right position* *Abilities of the good professional in the right position*

4. Practice		
Creating and maintaining an interpersonal relational space that is supportive and helpful	*Preparing* *Approaching* *Getting in touch* *Sensing and understanding* *Affirming and accepting* *Creating a shared perspective* *Doing/acting* *Evaluating and learning*	*responsiveness care*

5.3 Ethical foundation

Introduction

Modern theories on ethics of care form an important foundation of the tenets of good care described in the next paragraphs. I summarise a number of important notions from ethics of care that are supported by the empirical data in this study.

Good care is steered by 'good intentions', whereby it is morally charged. Any care professional is driven by a motivation to choose a helping profession. Many professionals simply state "I just want to help another human being", without wondering much about underlying motivations. When motivations are explored, these vary from a religious drive to help someone in need and curiosity about the complexity of human life to an interest in the

'technique' of curing interventions. What is considered 'good' is strangely enough rarely put in ethical terms or in desired outcomes for recipients of care. Moral dilemmas are generally not made part of the professional discourse (Van Doorn, 2008).

It is remarkable that quality of care is generally poorly connected to conceptions of quality of life (Noelker & Harel, 2000; Ruggeri, 2001). Literature on the quality of care mostly deals with technical forms of care which have to be performed in an efficient and effective way. Effectiveness is mostly defined as an outcome in terms of cure or of problem solving. Within this conception of quality of care, outcome is narrowed down to a - by a professional community preconceived - effect of an intervention. This might be different from the effect it has on or the result it has for the recipient.

Care embedded in a relationship

Joan Tronto (1993) considers care primarily as a practice, something one *does*. In her opinion, caring is always a culturally mediated and usually also an institutionally and professionally created practice. The practice is divided into four phases: *caring about* or observing a need for care; *taking care of*, or organising to relieve needs; *care giving* or direct provision of care; and *care receiving*. Four moral components of care correspond to these four phases, namely *attentiveness*, *responsibility*, *competence* and *responsiveness*. These components also came to the fore from my study.

Although Tronto puts forward the value of connectedness, she does not articulate the role of the relationship. Connectedness seems to be reduced to receiving care and the moral component of responsiveness. In paragraph 6.2.2, I criticise this notion, arguing that the notion of care receiving can be regarded in a much more dialectical way. I elaborate on this in my discussion of the notion of 'care responsiveness'. An important notion that is supported by the empirical data in this study is that the quality of the care process is to a large extent related to the quality of the relationship with the caregiver. This coincides with the view of Elisabeth Conradi (2001), who considers care as an "interaction among those involved". Care does not only take place within relationships, as new relationships are also developed through caring. Conradi argues that care may be seen as a form of social interaction that includes both relatedness as well as activity.

In the work of Baart en Van Heijst, the relationship forms the core of the ethic of care. Andries Baart (2001) has developed a theory on 'presence'. This theory is summarised in paragraph 5.4.1. Annelies van Heijst has developed a theory on 'human loving care' (Van Heijst, 2005; 2008), using insights from Arendt, Tronto, Verkerk, Walker, Ferry, Bauman, Moyaert, Sevenhuijsen and Baart. I use these insights for an ethical foundation for a theory of good care.

Human loving care

Like Baart, Van Heijst criticises current care practices that seem to lack compassion and humanity. In the past decennia, the care sector has been restructured on the basis of a business or market model, guided by economic and management principles. Many professionals have the feeling that they could not offer the diligence they would like to practice anymore. Care receivers often experience that they are being treated as numbers. When they are forced to use social services or health services, they often encounter

incomprehension and humiliation. At the same time, despite the neoliberal values of autonomy, choice and rights, which also appear in all policy papers on health care, they are often not in the position to choose or exert rights. As a result, distress is heightened instead of decreased.

Van Heijst uses the notions of Arendt and Baart to develop of a new ethical view of professional care. She shares the conceptions of Verkerk and Sevenhuijsen that the ethic of care should criticise rooted care patterns coupled with unequal social power relations. They all argue that the quality of care depends on the relations within which care takes place. Verkerk (1997) regards the ethic of care mainly as a moral perspective, while Sevenhuijsen (1996) regards it mainly as a moral activity. Van Heijst goes beyond this to approach the ethic of care as a normative theory, which revolves around the conservation of the vulnerable and valuable humanity of the weak and those caring for them. Van Heijst distinguishes four ways that constitute human loving care, namely competent availability, noticing the other as an incomparable individual, letting the other know and feel that he or she counts to the full, and being receptive. Professional knowledge and skills are placed in a larger framework, in which professionalism obtains an ethical meaning. Without this framework, care is reduced to mere technology or instrumental behaviour. Professional 'interventions' are a concrete appearance of the love for other human beings. It is the willingness to use capabilities and knowledge for whoever is in pain or desperate. (Van Heijst, 2008).

Baart (2004b) states that being "embedded in relations is the most basic form of being cared for, a caring good in itself and *sui generis* (unique, not reducible to anything else)" (p. 23). The ethical foundation of the relationship should be morally sound, which includes respecting the personal boundaries (including those of the personal niche) of the person, managing the relationship in accordance with its purpose (i.e. being beneficial to the wellbeing of the person) and not letting negative external forces damage the relationship. Baart says about moral soundness that it must be defensible on the grounds that it is just and is done according to justifiable motives by virtuous carers. What is just cannot always be determined in advance, or on the basis of set criteria. Moreover, it has to be decided on the basis of moral reflections and deliberations within the professional and social community.

Dignity and humanity

In Van Heijst's theory, professional practices are ethically loaded ways of acting, in which people can find each other in what they consider as good. Van Heijst names two connecting values, namely dignity and humanity. Care giving should be directed at preserving the dignity of injured and suffering people, and has to promote their realisation that they are worthwhile. In Van Heijst's vision, the ultimate aim is not to cure people, although it is great if this happens, but to assist someone in need, and not to abandon this person.

A basic value that is expressed in the theory of presence (Baart, 2001) is to be able to help others by simply personally witnessing their sorrow and pain. Adding this value to the ethic of care means that professionals go beyond their professional statute, and, if needed, provide support by sharing powerlessness in situations where nothing much can be changed. Here again, there is equality, and an understanding that both are vulnerable human beings with limited powers, and that only in sharing a situation can comfort be found.

Good care is based on the ethical premise that the vulnerability of the person in all its meanings (feeling unable, powerless, being socially marginalised and so on) is seen from a shared perspective: the subjective perspective of the person, which is never disputed, and the perspective of the professional doing justice to human dignity. This might also include fighting social systems or practices that increase or maintain disability. Therefore, the ethic of good care also has a political dimension.

Baart (2004) states: "Good care does not humiliate the care-seeker" (p. 22). Paradoxically, many people that use professional services encounter humiliation, as was also shown in the narratives in Chapter 3. Baart's elaborates as follows:

> Ironically these violations of human dignity take place within the bounds of law and rights: the provision of care is regulated, restricted and tied to specific conditions, with many humiliations resulting from the investigation into whether compulsory conditions are fulfilled and care may be provided. Here 'claiming your rights' goes hand-in-hand with the loss of self-respect and self-esteem. That is why we have to add the criterion of personal, political and institutional *decency* to that of virtuousness within the framework of legitimacy. (2004, p. 22)

Good care contributes to identity and autonomy. This means that good care will never damage the self-image of the person and break down his or her autonomy. Even in situations in which a person is in such a vulnerable situation that he or she is unable to exert autonomy, resulting in a life threatening situation, and professional action is needed, this action should be followed by autonomy-restoring practice.

Recognition

Recognition is an important cornerstone of an ethic of care. From the narratives it becomes clear that recognition is a basic need. People want to be affirmed as worthwhile fellow human beings. Experiences, needs and desires should be acknowledged. This is not a need exclusive to people with disabilities, but a universal need (Van den Besselaar, 2009). Honneth (1985) has developed a theory on recognition. He mentions three forms of recognition: love, respect and solidarity. I will elaborate on these forms in paragraph 5.4.4.

Inclusion and empowerment

Another ethical premise is to be 'inclusive'. This has two connotations. The first is that an important professional value is to include the person – to a certain extent – in your personal life, yet preserving personal and professional borders. A connection with a client is made on both a personal and a professional level. The second is that good care will always connect, reconnect or keep a person connected to the community (social networks and social domains). The purpose of good care is to support the person to become able to function and participate in the community. According to Baart (2004, p. 22), "care helps people to be (when possible, respected and useful) members of the human community, not to expel them from that community".

The ethic of good care takes into account aspects of powerlessness and power. One aspect of the tenet of presence is that the professional also remains present in a situation where powerlessness prevails. Here support is offered by sharing suffering and sorrow.

Empowering a person within the personal-professional relationship means creating and leaving the space for the other to develop him- or herself and become stronger, increasing autonomy. Through good care the other is helped to preserve and develop quality of life, and personal and social recovery is supported.

Sadan (2004) and Van Regenmortel (2008b) both mention in their writings on empowerment two fundamental ethical principles for empowerment, namely respect and recognition. They emphasise that the relationship between professionals and people who need their help can only be based on cooperation and the acknowledgement of the personal knowledge and perspective of the helped. Sadan (2004, p. 118) says the following in this regard:

> Respect for people is the basis for professional relationships. Respect is expressed in treating the request for help not as a sign of weakness or dependence, but as an expression of a need to receive professional service. Respect expresses itself in accepting people's interpretation of reality. Respect for a person and recognition of his strengths confirm his very existence and give it validity.

Discovering the good

An ethic of care provides professionals with an ethical framework. In this framework the relationship between a caregiver and a care recipient is the basis for the care process. The relationship is based on presence and the recognition of the other as a fellow human being (equality) *and* as a unique, special individual (inequality). In this ethical frame, frailty is acknowledged and conserved. The practice revolves around the recognition and restoration of human integrity and human dignity. This also implies that if human integrity is threatened, for example by systemic forces, this calls for emancipatory action.

The caring relationship revolves around a reciprocal, dialogical interaction, which turns around the discovery of what is considered 'good'. The caring relationship is empowering, in the sense that is aimed at restoring or increasing powers, contributing to physical, psychological and social wellbeing. In the conception of the good, it also becomes apparent what value should be strengthened, supported and obtained.

5.4 Tenets

In formulating a '*discourse on good care*', I considered the 'logic' of good care, the core elements that come forward in this logic that make this logic relevant, and the way in which the logic is operationalised in terms of professional acting. A number of notions emerge, which can be connected to theories found in the literature, and may also contribute to each of these theories. Within the discourse, six important angles can be distinguished: presence, shared perspective, diversity, recognition, autonomy and vulnerability and empowerment. As I mentioned before, I consider these angles as tenets, tasks that require study, reflection and an obliging effort to be connected to experiences in daily practice. The six tenets are embedded in an ethic of care, as outlined in the previous paragraph.

Table 5.2: Overview of the six tenets constituting the basic theories of good care

1.2 Tenets of good care
The tenet of presence (paragraph 5.4.1)
The tenet of shared perspective (paragraph 5.4.2)
The tenet of diversity (paragraph 5.4.3)
The tenet of recognition (paragraph 5.4.4)
The tenet of autonomy and vulnerability (paragraph 5.4.5)
The tenet of empowerment (paragraph 5.4.6)

The tenets might be regarded as the formative dimensions of 'connecting', a notion that I have developed on the basis of the empirical data in the previous chapters. In processes of recovery, people with a serious disease or disability try to reconnect. This reconnection has two aspects: reconnection to the self, to restore a personal identity, and reconnection to others and the community. Reconnection is a process of reintegration on an intrapersonal and interpersonal level. The process of reconnection to others also includes connecting to professionals who are in a care and support-providing role. In this sense, professionals (also) represent the community and 'the world'. When the past has been marked by alienation and social segregation, relationships have become vulnerable. Good care is care in which trust in fellow human beings can be regained.

From the perspective of the professional, the aim is to connect to a person in such a way that trust can be experienced. This is not only a condition for providing care/support services, but also to contribute to the reconnection of the person to him- or herself and the community. In the narratives, a connection experienced as understanding and supportive presupposes that the professional can connect to the perspective of the person, that he or she is able to attain a personal closeness, that the 'strangeness' of the other is respected, that matters of identity, vulnerability and autonomy are recognised, and that the person receives encouragement and support for self-growth. All of this starts with becoming present in the life of the other.

5.4.1 The tenet of presence

From my study the importance of the 'quality of the presence' of the professional in the life of the person emerged. Presence shapes and is shaped in the relationship that is the embodiment for good care. Presence can be established and sustained in many different ways. From the empirical study it becomes clear that there are many ways in which a professional can be present, but the bottom line is that this presence is experienced by the client as beneficial. The core of the tenet therefore is to be(come) present in such a way that this beneficiality is experienced.[31]

The presence of the professional is composed, or 'charged', by different elements (e.g. being there for the person, expressing understanding, connecting to the needs). Especially by people in vulnerable positions or with multiple problems and needs, it is experienced

[31] A key concept emerging here is 'care responsiveness'. In the logic of good care, the 'care' that is offered by a professional responds adequately to the needs of the person, in both a practical meaning (e.g. the need to solve debts) and an existential meaning (the need to be acknowledged). I elaborate on this notion in paragraph 5.6.2.

beneficial if the professional is 'care-full', i.e. if he or she expresses respect for the disability and consequent vulnerability and recognises all the needs within the life context of the person.

In Chapter 4, I identified connecting as an important category. For establishing a helpful relationship, the art and content of connecting is essential. From the narratives it came to the fore that notions such as contact, empathy, attentiveness, respect, equality, availability, moving with, commitment and dedication, sensitivity, seeing and understanding, responsiveness, continuity, companionship and sharing are important elements.

To become present in the life of a person is often preceded by being present in his life: 'being with' precedes 'being for'. The mere presence of the professional, as typified by the mentioned characteristics, already contributes to affirmation, safety and strengthening. 'Being present' is an important characteristic of professionals who are perceived as helpful by the participants in my study. From the analysis of the narratives in Chapter 3, it can be learned that this appreciation is not always there immediately (paragraph 3.10). Sometimes it is an appreciation in retrospective. By being and staying present, sometimes persevering if the person is not yet ready to make a connection, opportunities can be created for an engagement (*cf*. Lohuis, 2003; Lohuis, Schilperoord & Schout, 2008; Polstra, 1997; Polstra & Baart, 1994). Becoming present in a reciprocal way is then preceded by continuous outreaching efforts (*cf*. Burns & Firn, 2002; Mulder & Kroon, 2009; Van Doorn, Van Etten & Gademan, 2008; Van Veldhuizen *et al*., 2008).

Establishing and maintaining a connection by becoming and being present is a process that requires a certain position (see paragraph 6.1.2) and has a certain instrumentality, certain ways in which to do it (see paragraph 6.2). The presence should be an 'act of expression' in which acting and personal relationships are interwoven.

In the work of Andries Baart (2001), I found a number of notions that are supported by my study. Baart developed a 'theory of presence' on the basis of an extensive study conducted among pastoral workers in deprived neighbourhoods (Baart, 2001). The pastoral workers worked with people in extremely marginalised positions who were considered to be socially redundant. Baart discovered that the mere presence of these workers in these neighbourhoods already contributed to the wellbeing of people. He analysed and described what made the pastoral workers' way of working valuable. He found the following:

> The most important thing these pastoral ministers bring is the faithful offering of themselves: being there, making themselves available, coming along to visit and listen, drinking coffee together or sharing a meal, completing a small household project, running errands, accompanying another on a doctor visit, going for a walk together, visiting a grave site, sending a birthday card, playing together on the street, being there when a child takes its final swimming test. (Baart, 2002, p. 1)

The theory of presence is much more comprehensive than described here. It is a theory of good care based on an ethic of care, which considers care as concern and consists of four roots: competent care (doing what should be done), careful-ness (doing not only what is

needed, but doing it with attention, dedication and tuned to the other), caring (as a characteristic of the caregiver, which guarantees that what should be done is not only done with attention but is also persevered – good care is faithful care), and compassion (an expression by which the caregiver presents him- or herself in a relationship) (Baart, 2008, p. 52). Baart (2001, p. 798) conceives care as "an attentive involvement in human longing and neediness, a corresponding and accepted responsibility for it, the delivery of help that is experienced as proficient and the receptiveness for the reactions of care receivers".

The theory is critical because it puts forward other values than the current care system, which is using a market-based model aimed at organisational efficiency. The presence theory advocates (re)humanisation of professional care, which revolves around the person and his or her dignity, preciousness and need for protection.

Substantial emphasis is placed on "the cultivation of caring relationships", and not on problem solving. Nevertheless, the relationship proved to provide a fruitful foundation for actions that were conceived by the residents as supportive. The open unpredetermined approach of the pastoral workers, who connected in a natural way to the people they wanted to serve, led to an articulation of problems but also of satisfaction of needs and new hopes.[32] Keywords in the presence approach are patience, unconditional attentiveness and receptivity. Patience is needed to create the space necessary for attaching to the ordinary patterns of daily life in the neighbourhood and for adhering to local rhythms and social structures, but also for residents to attaching to the workers. In my study, the focus of the professionals was not primarily the neighbourhood, but the individual person and his or her biographical and social context. But the importance of patience, unconditional attentiveness and receptivity also has emerged from my study.

Other notions that appear in both studies are being available and reachable for the other, being 'interruptible', staying with the other, not abandoning him or her, and offering continuity. Being available and reachable has three dimensions. The first is a *physical presence*. Someone has to be reachable physically, to be available in person. The second is a *psychological disposal*. The professional must have an open (mind) and a hospitable attitude. He or she must be prepared to be receptive and to be(come) exposed to the presence and (full) representation of the other. Baart uses the notions of *inscribility* and *exposure*. The professional declares him- or herself 'inscribe-able', meaning that if the person wants, the professional can be part of his or her life and be of meaning to him or her. But this is done in a respectful, prudent way. By the term 'exposure', Baart means that the professional exposes him- or herself completely to the life world of the other. Exposure means opening up all one's senses to a world that is foreign to one. This enables the professional to get some insight into the 'inner world', the inside perspective, which can generate both understanding and compassion. Baart considers this essential for engagement and for really being present for the other. He emphasises that exposure is a process that requires a great deal of detachment from personal and professional socialisation.[33] The third dimension is of

[32] This logic of providing care is quite different from dominant practices, and can therefore be at daggers drawn with other care logics, for example those that are aimed at fast and efficient interventions. The studies on the presence approach and my study provide the evidence however that this care logic is effective in terms of personal recovery and social participation.

[33] In the exposure notion of Baart (2001), he speaks of four stages. In the first stage, the self has to be oppressed. A quick formation of opinions, or even emotional reactions, should be adjourned. So should the inclination to react actively. In the second stage, room should be created for the strange, or the other. Baart

a *social nature*. Many participants stated that the presence of this professional in their lives has a social meaning to them. Through this relationship they became part of the world. The professional was often considered a friend or a companion. Through this personal engagement, considerable social support can be offered.

From the studies on presence it is shown that professionals play a connecting role between a person and his or her environment. Social networks are enforced, both qualitatively and quantitatively (Baart, 2001; 2007). The same is demonstrated by other studies on approaches in which the establishment of close relationships with others is a central notion (Driessens & Van Regenmortel, 2006; Vansevenant, Driessens & Van Regenmortel, 2008).

In summary, the tenet of presence is to become, to be and to remain present in a way that provides a dedicated connection with a person. The tenet requires that ways are found to come close, to be attentive in an open but intense mode and to relate to the life world of the person. This requires calmness, sensitiveness and loyalty. It requires from the professional to allow the experiences and emotions of the other to come in, and not to avoid it or push it away. It requires an effort to connect to the person on multiple levels, to be compassionate, to recognise what is at stake, and to do what should be done. The tenet of presence can be regarded as the dominant logic of the professional performance as regarded by the participants. It colours and penetrates the being of the professional's behaviour.

5.4.2 The tenet of shared perspective

Good care is dialogical by nature. It can only be conceived through dialogue between the perspective of the person and the perspective of the professional. The tenet of shared perspective seeks to create the interrelational space of a common understanding.

The tenet of creating a shared perspective is related to the categories of connecting and understanding. This notion is meant to provide a way of thinking and working, which enables the connection of the two perspectives of professional and client. This seems extremely important for the other categories (affirming, assuring and strengthening).

In working with users of care, professionals bring their own perspective, as formed by their personal and professional socialisation, to the relationship. Users, on the other hand, also bring their own personal perspective. The perspective of the professional is confronted with the perspective of the person. There might be huge differences between the position, intentions and discourse of the professional and those of the person. In the studies reviewed in chapter 2 and the narratives in chapter 3, we saw many examples of how this resulted in misunderstanding, aggression and oppression. The crucial question is how the process will lead to an understanding from the side of the professional of the client's perspective and

calls this "purification". [Baart, 2001, p. 213] In the third stage, the person becomes susceptible to the other. This frees the way for what Baart calls "a concrete involvement in which responsibility is taken for what is presented, and which is requiring a response of compassion, effort, respect and care" (2001, p. 214). This is the fourth stage of exposure, which is the devotion towards the other, expressed in engagement, loyalty and support.

consequently to actions that are beneficial to the client, and under which conditions this will take place.

The core of shared perspective thinking is that the professional is able to change (in) his or her position to (understand) the perspective of the other. This serves three goals. One goal is to really understand the client and his or her needs. The second is to be able to create a relationship in which good care is possible. The third goal is to see oneself, as a professional, from the position of the other. This enables one to monitor behaviour through its effects on the other. Any relationship of people working together is determined by some common perspective, something that is shared or agreed on. The same is true for the relationship between a professional care worker and a client. In care interactions it is clear that when this consensus is lacking, disappointed clients who feel misunderstood and abandoned, or unwanted and resisted interventions, are often the result.

A common perspective is not the same as having an identical perspective. A common perspective means that there is a shared area of understanding and beliefs that provides the basis for securing and strengthening. It also means that differences are respected and even articulated. After all, only in complementarity can the professional add value to the quality of life of the person. So, although there must be some shared perspective, within this perspective the contributions of the professional, having a different position and different qualities, should be apparent. From the point of view of strengthening, the talents and contributions of the person should also be highlighted as well as the efforts that he or she (or his or her network) can make, which are different from the contribution of the professional.

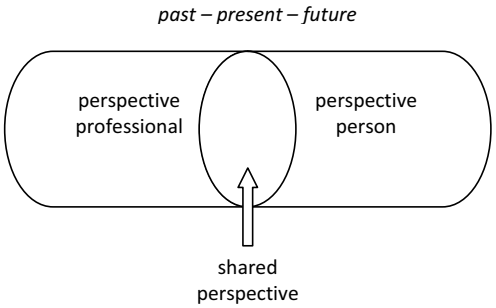


Figure 5.1: An interaction of perspectives

Sharing a perspective also means that the *boundaries* of this perspective are clear. Boundaries between individual perspectives and a shared perspective should be clear in order to respect each other's position, responsibility and autonomy. Without this respect, a shared perspective is probably not possible. Within the shared perspective, boundaries may be formed by what is within reach or power. Boundaries may also be formed by the ethical norms of the professional. A professional might not agree on some aspects of the behaviour of the client, for example heavy drinking or being aggressive to his or her children.

A shared perspective is also created by articulating *differences*. There certainly is a difference in *role* and *position*. The role and position of a care recipient are different from

those of a professional. There may be differences in *opinion*, which, once articulated and acknowledged, can become part of a shared perspective. Other differences are the result of *diversity*: differences in gender, age, cultural background, religion, skin colour and so on. I also consider a different biography, coloured by experiences with a serious disease, disabilities and the (mental health) care system, as an important aspect of diversity. Dealing with these differences is part of the tenet of diversity (see paragraph 5.4.3).

Boundaries might not always be clear. There are always things that cannot be known or foreseen. Unexpected things can happen, both negative and positive. Since a perspective always changes, this is also the case with a shared perspective.

Achieving a shared perspective can be realised through a process of discovery and learning. From this study it is apparent that this process by itself is already an important part of good care. Thus, working on the creation of a shared perspective is both *part of* and a *condition for* good care. Getting understanding is achieved by giving understanding. It is clear that the different categories of good care reinforce one other.

5.4.3 The tenet of diversity

The exposure to the perspective of the other and the attempt to understand imply being confronted with a world that is often quite different from the personal world of the professional. This poses the tenet of diversity. The core task here is that the client *is* and *can be allowed* to be different, and that this difference is *kept intact*. Although participants in my study stated that they value being treated as equal, they were not referring to being equal in terms of personality or position, but to the act of being taken seriously as an equal human being, not less valuable than others (including the professional him- or herself).

The professional discourse is not aimed at stashing away difference but instead at acknowledging it. A person might be different because of his or her psychiatric experiences. These experiences form a part of his or her identity. Through my study it was identified that an important aspect of a recovery process is to (re)discover or (re)adjust the personal identity by incorporating the differences that make the person a unique individual. Through the tenet of diversity, the professional (also) enables the other to explore and confirm his or her personal identity (see paragraph 5.4.4).

In creating a shared perspective, identifying and acknowledging diversity is an important aspect. From the framework of shared perspective, this act is reciprocal. According to the narratives, professionals who are considered as really helpful are perceived as different from other professionals. This uniqueness appears especially when a professional is not perceived as ‘just a service provider like any other service provider’, but as someone unique or ‘special’.

I will explore this tenet using different theories on diversity, which all contribute to the ethical foundation and the tenet of presence described before.

(1) Annelies van Heijst’s theory of care ethics (2005) acknowledges the differences between people. These are not only differences in terms of age, gender, culture, religion or ethnical background, but also differences in terms of physical and mental conditions. A great

moral challenge is to hold together *inequality* and *equivalence*. She speaks about a shared structure of neediness. The surface structure of the care relationship is the unequal and urgent neediness. There is a pressing need and this calls for a careful response. Underneath lays a mutual neediness, which is present in both care receiver and caregiver. This is the deep structure of the care relation. To and fro, giver and receiver need each other in order to lead a real human life.

Van Heijst argues that this shared meaning should be kept intact. In this regard, an important principle for good care is to acknowledge that in the interaction between a caregiver and a care receiver there is both equality and inequality in needs. She refers to the work of Arendt, who wrote that it is essential for human beings to be both equal to each other and also be unique individuals.[34] Arendt (1958) and also Böckle (1995) state that if someone really wants to feel like a human being, his or her uniqueness should be respected.

(2) Herman Meininger (2007) underlines the importance of articulating diversity in abilities. He approaches the issue of diversity from the perspective of social integration. In his view, social integration is not a characteristic of a situation or of people in a situation. He considers social integration as follows:

> ... an inter-personal process which helps to see, acknowledge and appreciate persons who feel themselves as a strange other, or are seen by others as a strange other, in their own identity, so not despite, but *with* the features (limitations and differences) which are perceived as strange. (Meininger, 2007, p. 13)

I would like to consider the connection between a professional and a recipient as a basic form of social integration. The professional has to find a way of integrating the discourse of the other, which per definition is strange to him or her, into his or her own discourse. The means to do this is the personal encounter and dialogue with the other. The result of this integration process is a shared (integrated, inclusive) perspective.

(3) Halleh Ghorashi (2006) has developed a theory of diversity with regard to the integration of minorities. Some of these insights are also valuable to the diversity issue that forms part of the discourse on good care. She sketches a development in postmodern society in which there is an increasing pressure on people with a different cultural background than the original inhabitants to assimilate. In this discourse there is an implicit assumption of non-conformity. Differences are problematised. People who are culturally different are considered deviant to the prevalent societal norm and put aside in a separate category. Ghorashi (2006, p. 14) calls this “the basic assumption of categorical thinking”. Efforts are made to help them to adapt, but they are placed in a position of an underclass citizen and a dependent receiver of welfare services. Ghorashi criticises this line of thinking, and pleads in favour of an approach that starts with the recognition of people with a

[34] In modern care there is constant tension between the tailoring of care to the uniqueness of the individual and the standardisation of care. The standardisation of care in protocols, rigid treatment programmes and beaconed interventions is both a result of the aim to reduce costs and the importance that is given to evidence-based research dominated by randomised controlled trials, which basically provide evidence of an ‘average’ patient, thereby ignoring the uniqueness of and the differences between people.

different identity. She wants to promote a "diversity-inclusive" society, in which the dominant discourse is no longer adaptation to one form of autonomous citizenship as a solution to all social problems (Ghorashi interviewed by Kal, 2007, p. 22). She places this against the background of a flexible notion of identity, not as an unchangeable state, but rather as a process in which it obtains new forms "at the cross point of experiences from past and present" (Ghorashi, 2003, p. 20; see also Hall, 1991). Identity is then "the narrative of the self" (Giddens, 1991, p. 201), which constantly obtains new forms in an area of tension between what has been given originally by character and upbringing, and what dominant discourses impress upon one in the course of life (Wekker, 1998). Contextual factors constantly influence human behaviour. People need a safe space in order to reflect on both their own (cultural) identity and the way they want to relate to the dominant (cultural) identity. Social recognition is essential for human development. Ghorashi states that this recognition can offer the possibility for a positive self-definition of individuals and groups. That's why the recognition of the difference forms the most important basis for a healthy democratic society.
She cites Taylor et al (1994, p. 54) stating: "refusal can inflict damage to those to which recognition is denied".

(4) Doortje Kal (2001) has developed a theory of creating hospitality in the community for people who suffer because of psychiatric experiences and who long, like any other human being, to belong to the world. A major obstacle to social inclusion is when differences are not seen and understood because the suffering of the person cannot be 'presented'. She uses the notion of the French philosopher Lyotard who speaks of "unpresentable suffering" that leads to an "unnameable contrariety" (Kal, 2001, p. 59). According to Lyotard, "controversy about a controversy" develops when the other does not experience the controversy as such, thereby rendering the experience of the person unpresentable. This puts the person in a situation of speechlessness and isolation. The heart of the controversy is suffering from the injustice that the own position (experience, illness, memory) cannot be expressed in a situation in which exactly that position is at stake. Lyotard states that an involvement with the person in this situation puts one in a problematic position because that which can be sensed but which is an injustice not yet articulated, is contradictory to a mainstream discourse on public (re)presentation and articulation. It requires from professionals (and other citizens) the courage to stay with the person although it is not possible to articulate what the matter is and what should be changed (see also Baart, 2001). According to Kal (2001, p. 60) "[…] we have to accept and endure this frailty, as a form of solidarity". Space has to be created for an indemonstrable difference. Kal uses the notion of hospitality to make the connection between the speechless and the public. She uses the notions of Derrida who speaks about "allowing admission to alterity" (Kal, 2001, p. 61). He connects this alterity to the idea of the Greek *chora*, the metaphor of the city square as a meeting place, which offers space for mediation and border crossing between parties, without one having to lose oneself in the other, and the other having to assimilate with one's identity. I think this idea is important for my thinking about the interpersonal relational space (paragraph 6.2.1) and the social niche (paragraph 3.9), because essential characteristics of these are that there is the assurance that differences may exist and that they are at the same time bridgeable.

Kal proves that it requires considerable effort to create these hospitable niches. An example of such effort is to "suspend the performance society" (p. 58), and to work on a "re-interpretation of normality" (p. 63). If the other is judged on the basis of his or her 'utility' for the labour process, or his or her fit with the care system, the other is immediately excluded and no room is left for being different or for personal expression. For creating a hospitable space, it is not enough to have tolerance, to *let space* to others who are different, but also to *make space* (Janssens & Steyaert, 2001). This is a more involved form of tolerance, which starts from a sincere interest in the 'being different', something that has to come from both sides. The core is the will to meet the other. Ghorashi says that this requires the ability to make space, to "set a step aside" (in Kal, 2007, p. 1). Once this space has been created, it is important to maintain and defend it.

Kal is speaks of an *intermediate stage* to allow admission to alterity:

> Taking hospitality seriously requires reflection on existing relations – and on myself as part of these – to see what is at stake. The realisation of other values requires to leave common paths and to dispose of set patterns to really approach the other. (2001, p. 62)

(5) Another way of making room for the difference from the side of the person in a marginalised position is what Janssens and Steyaert (2001, p.117) call "resisting in the margin": withdrawing oneself from the dominant discourse and producing one's own story from one's position as 'being different'. In this regard, the person does not continuously react to the demands of the dominant discourse, but takes the time to claim his or her own space for his or her own development and for constructing an own narrative. The combination of calmness, patience and deceleration provides the opportunity to experiment, to explore the differences inside the own personality and the differences from (and similarities to!) other people in society. Sometimes this 'resisting in the margin' develops in relationship with others who share similar experiences. This is seen happening with people who join the recovery movement in psychiatry. Inside an own cultural and social niche, stories are produced, exchanged and connected, thereby creating emancipatory forces that not only contribute to the (re)creation of personal identity, but also to a collective identity. In the USA, for example, people label this identity as 'survivors of psychiatry'. In this form, it can also develop as a collective struggle for recognition.

In summary, the tenet of diversity relies on the tenet of presence. It requires from the professional to respect the strangeness of the other and to make room for it. The core task here is that the other is and can be allowed to be different, and that this difference is kept intact instead of being ignored or neutralised. The professional works on the basis of the attitude of being open to the 'being different'. The wonderment about this difference becomes a challenge and an opening for dialogue (Heyndrickx, Barbier, Driesen, Van Ongevalle & Vansevenant, 2005).

Benjamin (1998) has noted that any similarity between two people coexists in an uneasy balance with their inherent differences. This requires from the professional continuous efforts to fine-tune his or her understanding to 'get it right'. This is the only way in which a constructive interpersonal space can be created (see paragraph 6.2.1).

In addition, tension caused by differences can be used to help the other in his or her search for recovery of the personal identity. Working with the tenet of diversity may require from the professional to assume an intermediate position: a position between the alterity of the person and society. This position is characterised by abstaining from actions that might be expected from society and its institutions (which is consistent with the tenet of presence), thereby creating the hospitable niche, which offers the space for the person to articulate the uniqueness and for the professional to understand the perspective of the other (which is consistent with the tenet of shared perspective). By creating hospitality in society, the professional may contribute to mutual understanding and recognition between the person and the environment, thereby promoting social inclusion.

5.4.4 The tenet of recognition

Another important tenet for the professional is to recognise the other. From the narratives it becomes clear that recognition means addressing a need of being affirmed as a worthwhile fellow human being, and acknowledging experiences, needs and desires. To be able to offer recognition, a professional has to understand the person and his or her situation and be sensitive to the needs connected to recognition. The theory of Axel Honneth (1995) teaches more about the notion of recognition. Honneth mentions three forms of recognition, namely *love*, *respect* and *solidarity*.

(1) According to Honneth, *love* is the first and founding form of recognition. Love is described by Honneth as the recognition of the needs and the emotional dependence of a specific other. Love is the condition for the development of self-trust, and without this all other types of mutual recognition are impossible. Honneth refers to object relation psychology and developmental psychology, which describe the attachment (providing basic trust and security) and separation process between a child and a mother, eventually leading to the development of a unique and integrated identity. Honneth maintains that during adulthood, love between individuals keeps a precarious balance between us-together and each -apart.

(2) The second form of recognition is *respect*, which is linked to self-respect. Self-respect does not refer to having a favourable opinion about oneself, but to the awareness that one has rights that make one equal to others. Honneth attributes three meanings to self-determination or autonomy. The first is moral autonomy, or self-legislation, in accordance with general and impartial principles. The second is the anthropological autonomy, or the ability to direct one's own life. The third is personal autonomy as a (civil) right, or the socially accepted title to form the own life, both morally and legally. Honneth defines respect in the sense of respecting the other as bearer of equal rights. This conception seems more social-political by nature and applies to each human being, without it even being necessary to know the other party personally. Van Leeuwen (2003) points to another dimension in the theory of Honneth: the respect for bonds, or the importance to belong, independent of achievements. The social environments to which the person belongs should also be respected. Van Heijst (2008, p. 35) remarks that especially for people in need of care, this is a rich thought. When we transfer this idea of respect for both the individual and his or her social context to long-term care, it means that both should be given attention and should be supported.

Honneth relates self-respect to one's sense of possessing of the universal dignity of persons. To have self-respect means to have a sense of oneself as a person, that is, as a 'morally responsible' agent. This relation-to-self is also mediated by patterns of social interaction, which are partly organised in terms of legal rights. Rights ensure the real opportunity to exercise the universal capacities constitutive of personhood. This is not to say that a person without rights cannot have self-respect, only that the fullest form of a self-respecting autonomous agency could only be realised when one is recognised as possessing the capacities of a 'legal person', that is, of a morally responsive agent. The moral principle of justice underlies legal rights.

If someone gets a serious disease and is hospitalised, this is often paired with a loss of rights or the possibility to exercise rights. The sense of being able to act as a 'moral agent' is often lost, also due to the (mental) health care system. In the recovery narratives, the 'restoring of dignity' is an important part of the process. Having one's basic human and legal rights recognised is considered a good that contributes to self-respect.[35] This is connected to the notions of citizenship, autonomy and social inclusion.

(3) The third form of recognition described by Honneth is *solidarity*, which is related to esteem. For Honneth, esteem is accorded on the basis of an individual's contribution to a shared project. In order words, it requires an effort, an active stand. Whereas self-respect is a matter of viewing oneself as entitled to the same status and treatment as every other person, esteem involves a sense of what it is that makes one special or unique. Self-esteem is induced by the social esteem of others. According to Honneth, this must be found in something that is valuable. Van Leeuwen (2003) notes that 'social appreciation' is a more adequate description than social esteem. Based on my study I may add that appreciation should also entail *valuation.* Where respect for the other as the bearer of equal rights can be given regardless of a specific person, appreciation or valuation requires a particularisation for what this person can, does or is. The notion of appreciation is linked to self-appreciation. Van Heijst (2008) states that self-appreciation always comes from others. Although one can assess one's own worth, the recognition of characteristics or achievements comes from the environment, and is also based on social and cultural norms. Van Heijst notes that in our modern society, appreciation is mainly coupled with what one is doing and able to do. The recognition of rights (allocation of equal rights) and social appreciation (allocation of approval) are decoupled.

Van Heijst and others argue that recognition is not, or should not, always be a result of a struggle, but should also be an unconditional *gift*. In Honneth's work, this is only implicitly mentioned in the first form of recognition, namely love (when he speaks of the love between parents and a child). Van Heijst states that it can also be extended to the other forms of recognition. In a number of the narratives in my study, the *gift of recognition* was experienced as surprising, liberating, encouraging and supporting. Recognition as a gift is also experienced when professionals show commitment and dedication, because this expresses valuation. Van Heijst extends the notion of love as a form of recognition beyond the private sphere of children and their parents. She states that many professionals 'love'

[35] Although tempting, I will not go into the subject of coercion and compulsory treatment in psychiatry, which in itself cut off people from a number of legal rights. But from a number of narratives which I analysed, it becomes clear that coercive care has an enormous negative impact on self-respect and autonomy.

their work, because they love (working with) people or that they mean something valuable to other human beings. This often forms the core in helping relationships. Professionals cannot work without recognition, the recognition that their love and efforts are appreciated –.the fact that their work contributes to the fulfilment of the (respect of) rights of people in need of care, is to them often a secondary or unconscious motivation.

Disrespect

In Honneth's recognition theory, all three forms of recognition are essential. He also connects three forms of disrespect to these forms of recognition, namely physical violence, exclusion from (equal) rights and depreciation, i.e. not being seen as a full human being. Because in essence, forms of exclusion, insult and degradation can be seen as violation of a person's self-confidence, self-respect or self-esteem, the negative emotional reactions generated by these experiences of disrespect provide for Honneth the theoretical basis for social critique (Anderson, 1996).

Van Heijst (2008), putting the theory of recognition in the framework of (an ethic) of care, argues that simply having rights, such as being entitled to professional care when needed, is not enough. Honneth does not delve into this, because he assumes that every human being is capable of expressing and exercising this right. Van Heijst critiques this by arguing that many people are not able or not in a position to get recognition for their legal rights. Many people cannot gain access to health care, or find their way in the complexity of care systems. Institutional care is furthermore characterised by asymmetrical relationships that do not offer opportunities for equal and reciprocal relationships. One could argue that changing health care to more symmetrical relationships will do justice to recognition, both in terms of respect and in terms of social appreciation. Within the framework of institutional care, people need besides the different forms of respect, also love and valuation.

My study shows that in the narratives, recognition is often refused. Evidence of physical violence, exclusion from (equal) rights and depreciation as a human being was seen. (paragraph 3.12). No wonder that people's self-confidence and self-respect are damaged. When looking at the core elements of good care, this care is loving, respectful and appreciative. Respect goes further than simply respect for general civic or social rights. It is the respect for the frailty (of both the person and the situation) and for the personal niche. It is the respect for the personal views of the client. It is the respect for impediments that may render a person unable to express him- or herself. It is the belief in a dialogue in which views can be exchanged and decisions can be taken that seem morally sound.

Recognition in the process of recovery

When comparing the theoretical notions of Honneth with the findings of the studies on recovery in chapters 2 and 3, it becomes apparent that recognition can be regarded as a precondition to identity formation.

Honneth regards the struggle for recognition as a precondition for self-realisation. In all the phases of the process of recovery, a struggle for internal recognition and a struggle for external recognition can be seen. Internal or self-recognition is realised through the recognition by others. The social relations with peers form an important source of recognition, but also in the relationships with professionals numerous acts of recognition

can be found. Already in the early phase of the recovery process, when the person struggles with the disease, this is often accompanied by the struggle for recognition from others. In these turbulent times, there is an urgent need for respect, esteem and confidence, which are needed to maintain (often a very thin and fragile) sense of self-respect, self-esteem and self-confidence. In the second phase of recovery, with its emphasis on reorientation, identity is reformed. According to Honneth, the very possibility of identity formation (and I suppose also identity reformation), depends crucially on the development of self-confidence, self-respect and self-esteem. These three modes of relating practically to oneself can only be acquired intersubjectively, through being granted recognition by others whom one also recognises. As a result, the conditions for self-realisation turn out to be dependent on the establishment of relationships of mutual recognition. For professional care, this implies that from the perspective of the professional, (a contribution to) recognition can only be possible if there is intersubjectivity in the relationship.

My study confirms that revealing personal value is an important aspect in recovery. However, in the dominant discourse on (mental) health care, the emphasis lies on what is wrong. People are often devaluated to a patient or a disorder. Personal goods are apparently erased from the identity. In a discourse on good care, there is an active search for what makes a person unique and valuable. Honneth situates esteem in "the horizon of values of a particular culture" (1995, p. xvii). Solidarity is the term that Honneth uses for the cultural climate in which the acquisition of self-esteem can become possible. The notion of solidarity can be applied both to the climate of the interpersonal space between professional and client and to the climate of the community or society (for more information on the latter, see paragraph 5.5.3). Honneth states that one can only properly speak of solidarity when there is some shared concern, interest or value. He refers to the presence of an open, pluralistic, evaluative framework within which social esteem is ascribed. When I narrow this down to the interpersonal space between a care provider and a care recipient, this is highly characterised by a commitment from the side of the professional to be in solidarity with the client. The good that is perceived by the client is that he or she is valued as someone who is esteemed as a unique person. There is not only an active search and acknowledgement of what makes someone different, but also of personal values, strengths and contributions. In the logics of good care, this also means that the professional aims to engage the person and his or her environment in a 'shared project', a common endeavour to improve quality of life (Wilken & Den Hollander, 2005).

Identity can be seen as an authentic biography that gives answers to questions such as Who am I; Who was I; and Who do I want to be? (Bluck *et al*., 2005; Giddens, 1991). Giddens states that a person's identity is not found in behaviour but "in the capacity to keep a particular narrative going" (1994, p. 54). Taylor (1989) has introduced the concept of 'dialogical identity'. The basic idea is that human identity is formed through interaction with other human beings. Someone's self-worth is to a large extent built on how others look at you and interact with you. The attainment of identity is thereby linked to the recognition a person receives from and gives to others. The self is an open concept rather than a substance. This notion is also described by many other contemporary philosophers, such as Levinas, Arendt and Bauman. The self cannot fill itself, so it has to be filled by different sources. An identity is formed from birth through interaction with other people in the environment, and continues to be formed throughout the whole life. For a healthy

development of identity, social cohesion is essential. Identities are formed within a context of interaction with others, and are influenced by psychological, social and cultural factors.

Box 5.1 Identity formation

In general, identity formation is subject to frictions, different powers and resistances (Taylor, 1991), but in the case of certain restrictions (biological, institutional), mechanisms of power and conceptions of 'truth' within subject formation (e.g. the diagnosis of schizophrenia) will have a specific influence (Foucault, 1977a; 1977b).

The notion of identity is subject to cultural conceptions and has changed over time. From the beginning of the 18th century, something which might be called modern identity develops in Western society. With the ceasing of God as the only leading image in thinking about oneself, reflexivity as essential part of Western thinking was directed towards the individual him- or herself. This self-reflexivity, by self-research and self-control, became the core of modern identity and took shape in individual, self-responsible independence (Taylor, 1989). Taylor emphasises that the development of a self-reflexive identity was related to modern conceptions of 'the good life'.

Over the past decades, under the influence of the development of democracy, civil rights, the relationship between private and public spheres, capitalism and institutionalised labour, a late-modern or postmodern identity has developed (Benhabib, 1992; Giddens, 1991), This can be described as self-reflexive to a high degree and directed at autonomy and authenticity. Differences between modern and post-modern identity are the fluency of life trajectories and a morality that is no longer aimed at virtues and duties.

The course of life is no longer determined by fixed transitions (from school to work, to marriage and family and so forth); work has become much more flexible, education is a continuous activity, relationships vary in form en duration. The world has become more and more of a "liquid modernity" (Bauman, 2000) and a "network society" (Castells, 2000). In addition, consumption patterns, with a multitude of life styles, determine the value of life.

Morality gets the form of a self-reflexive testing to personal norms and values, although these are also formed through the interaction with others. On the late-modern individual rests the duty to be the author of a successful personal life. This form of individuality entails something pressing: People are not only *allowed* to decorate their own life, they also *have* to do so. Identities are formed against this background.

In the framework of this study, the identity formation of people who are experiencing serious mental, intellectual or physical troubles is relevant. Although a healthy and 'beautiful' body (beautiful according to particular norms) is emphasised to a great extent in our culture, at the same time, an unhealthy or deviant body does not have a place in the postmodern discourse on identity. The sick, mad or even dead body only figures in a negative sense, as something that falls outside the perspective of a 'normal life story'. They are considered an essential 'other'. Giddens (1991) speaks about excluding existential experiences. According to Van Heijst (1993), the absence of the sick body is a result of a defect in our culture, of a 'social-psychological defence mechanism of suffering'.

Identity can also be defined as the symbolic structure that enables a person to maintain continuity and consistency amid constant changes – in events and social positions (Belgrad, 1992). This symbolic structure makes it possible for a person to be a subject, to say 'I' and to experience him- or herself as a special 'I'. In the course of life, people develop a growing awareness of identity. People can identify themselves more and more as 'this is me' if they

take responsibility for their own life, if they recognise what they have done in the past, what they do in the present and what they want to do in the future as their own life history, as the result of their actions, aspirations and personality. A conscious identity is formed in a narrative way, by reflecting on what has happened, by attributing meaning to actions and events, and by drawing lines from there to the future. In this sense, identity has a narrative nature. People's identity becomes visible in the stories they tell. Although there is a basic pattern of development, identity formation is an ongoing process. People form an identity in communication with others. This communicative dimension implies also that answers to the existential questions are implicitly determined by moral conceptions of what is 'good' (Coupland & Nussbaum, 1993; Freeman, 1993).

Severe events, such as a serious disease, can lead to the fragmentation of an existing identity (Hoogenboezem [2003, p. 256] speaks of "crumbled identities") and the necessity of forming a new, integrated identity. This is the case in most of the narratives in Chapter 3. In case of serious mental illness, where cognitive functions can be impaired, it requires the special endeavour of recreating an identity using the same functions that have played a role in the deformation of identity. Here, the communication with others obtains extra significance. Being able to tell the story and to share reflections are important support pillars to regain coherence and continuity.

The development or reconstruction of identity is an important facet of the recovery process. The person (re)constructs his or her identity or self through a process of discovery (Hatfield & Lefley, 1993) and re-historisation (Petry, 2003). Young and Ensing (1999, p. 9) describe this process as "learning new perspectives about oneself, one's illness and the world" and characterise it as "a process of learning and self-redefinition: gaining new perspectives about self and illness" (Young & Ensing, 1999, p. 219). Often, traumatic experiences (either caused by the disease or by negative experiences before or after the onset of the disease) have to been worked through, which is also a process of bereavement. A new sense of self has to be reconstructed; a self that is both acceptable by the person him- or herself and that has to fit somehow in the external world. After reaching a point where people are stable enough, some sort of internal inventory is performed to find out which parts of the self remained intact. As time passes and recovery evolves, people often rediscover parts of themselves that they had assumed were lost. However, in this process people also discover new potentials, which lead to unexpected possibilities for growth and development. New insights are also gained about the relationships between self and illness. People tend to reconstruct a stable sense of self that incorporates illness as only one aspect of a complex, multidimensional self. It appears that people's sense of self-identity gradually expands, allowing them to place their illness into a new perspective. It often means moving away from the illness identity towards 'being a person with multiple qualities and also some disabilities'.

From the narrative analysis it becomes evident that professionals play an important supportive role in the restoration process of personal identity. A professional should be aware of the presence and importance of this process for people who are struggling with a loss of identity because of their personal experiences. A basic stand is to acknowledge the presence of deviancy (an aspect of personal uniqueness) as being an integral part of (everybody's) life and identity. Recognition from the part of professional caregivers opens

the way to support recipients to develop a new life story and to work on their identity and autonomy.

5.4.5 The tenet of autonomy and vulnerability

Autonomy can be conceived as (re)attaining self-direction. It is connected to self-consciousness and a feeling of control. It is related to the notions of agency and responsibility, according to which human beings are conceived as the agents of their own life and as responsible actors in the human community.

From the narrative study it is apparent that autonomy and dependence can be there at the same time. Because of their specific disability, people might well trust part of their autonomy to others. Autonomy is realised in connection with others. The main feature attributed to autonomy seems to be that (finally) people themselves are the ones in control of decisions. This is an important discovery for the discourse on good care. Good care always facilitates the autonomy of the other, starting from strengths and vulnerability. It leaves people in control and restores the ability to exercise control as much as possible.

In order to understand this tenet, I elaborate on the notions of both autonomy and vulnerability. These notions are also related to the tenets of diversity and recognition as discussed previously.

Autonomy

From the narrative analyses it becomes clear that the concept of autonomy is problematic for many people dealing with the consequences of traumatic life events and severe psychosocial vulnerability. Their desire for autonomy is connected to the (re)construction of a personal identity and to the desire to direct their own life. The values of self-respect, self-confidence and self-esteem as constitutional elements of recognition are all related to the notion of vulnerability. The notion of autonomy should be seen in the light of vulnerability in its general and specific forms, the concept of the personal niche and the development of identity. Together they form a dynamic interrelated and differentiated construct.

In the narratives, there is a constant struggle to insert oneself in the dominant discourse on the 'autonomous, self-reliant citizen', because this is inevitable for a contemporary, 'ordinary life'. People have to deal with the paradox that on the one side they want to be like other people, but on the other side having a disease or disability is considered by society as *not* normal. People have to find a form of autonomy that is quite 'liberal'. In a study by Ingrid Baart (2002) on the development of identity in the life of people with a chronic illness, she concludes that they bridge this paradox by emphasising that all people are dependent, i.e. people who depend on care and support can also be autonomous.

Andries Baart (2007) remarks that nowadays, autonomy is often taken for granted, as though all citizens are capable of being autonomous and know how to be independent, how to live their own life and how to develop. For many people, this ideal (or even ideology) of autonomy seems to be far away, and by not being able to comply with this social norm, they are even more excluded from mainstream society. Over the past decade, a countermovement has developed. The notion of autonomy itself seems to be criticised and

reconsidered. The notions of interdependence (Condeluci, 1991) and caring citizenship are gaining influence (Wilken, 2005b). Assertive outreaching care, which 'meddles' with people in deplorable circumstances, is allowed again (e.g. Van der Lans, Medema & Rakers, 2003).

Box 5.2 Thoughts on autonomy

Within the context of neoliberal society, autonomy is regarded as a central value. It is a good that has been acquired through social action by groups who felt oppressed in the 60s and 70s, such as women, homosexual people, patients and ethnic minorities. They wanted social recognition and independence. In ethics and care, autonomy refers to the right or the possibility of a patient or client to determine for him- or herself what should be done.

Baart (2007b) refers to the Humanistic League, which describes autonomy as follows: Autonomous people want as much as possible to determine their own life. They look themselves for what is valuable and important, and dare to look critically at themselves and at others. Autonomy is coupled with self-realisation. It does not only mean 'freedom from coercion', but foremost striving for what one considers to be good, beautiful and valuable. Autonomy is a task, a person is not born with it, and it does not come to one just like that. It requires self-thought, but also the courage to doubt, sometimes not to know, to be unsure, and yet to make a choice anyway. Autonomy has to do with developing one's identity, with the art of living, with reasonableness and morality. The autonomous people try to set their own path in life, from which they derive meaning with which they are satisfied and in which they believe.

The pursuit of this kind of autonomy is widely supported in our modern Western society. Tension arises when this notion is connected to vulnerable people who have limited possibilities for this pursuit. As stated in paragraph 5.3, in health care, despite the neoliberal values of autonomy, choice and rights, they are often not in the position to choose or exert rights (Baart, 2001; Baart, 2007b; Hoogenboezem, 2003). According to Baart (2007b, p. 2) "autonomy should not result in a situation in which one is allowed to die all alone due to loneliness, drugs, madness and an untameable temper, because one choose so oneself."

Different studies show that people, for different reasons, do not ask for help when they need it (Nuy, 1998; Van Doorn, 2002; Hoogenboezem, 2003). Autonomy or the right to self-determination does not legitimise a professional attitude of aloofness, but requires professionals to assume a normative position, based on the ethical norm that the need and the vulnerability of the other make fellow human beings responsible (Marcel, 1969).

Anderson and Honneth (2005 p. 129) state the following:

> "The drive to maximize […] liberty thus seems to rely on a misleading idealization of individuals as self-sufficient and self-reliant. This focus on eliminating interference thus misconstrues the demands of social justice by failing to adequately conceptualize the neediness, vulnerability, and interdependence of individuals. If, by contrast, we recognize that individuals – including *autonomous* individuals – are much more

> vulnerable and needy than the liberal model has traditionally represented them as being, a very different picture of the demands of social justice emerges."

The authors propose a recognitional model of autonomy that emphasises the intersubjective conditions for being able to lead one's life as one's own. This is consistent with the ideas of Reindal (1999), who points out that personal autonomy should not be confused with the ideology of independence. Reindal underlines that this mutual dependence is fundamental to the human condition. Professionals tend to define independence in terms of self-care, and measure this by looking at self-care activities. People with disabilities, however, define independence more as the ability to make decisions about their own life. The notion of "control in principle" means that people have control despite the fact that others may execute tasks on their behalf that they cannot do themselves.[36]

I would like to argue that professional care should contribute to another conception of autonomy in late-modern society. This concept is based on the respect for and freedom of self-determination *and* on the notion of interdependence. Taking responsibility for the 'human being' of others, and thereby doing well for others, is a central value and a duty as well. In this conception autonomy is connected to human dignity.

In the next sections I will elaborate on the notions of vulnerability, identity and social participation as related to autonomy.

Vulnerability

A number of participants in my study seemed extremely vulnerable, caused by their psychiatric illness. Others had had episodes in their lives in which they were made extremely vulnerable, for instance due to oppressive circumstances in their youth or due to traumatic events. These circumstances and events had had a serious impact on development and self-realisation. They were strong impeding factors for autonomy and identity formation. An important stage of recovery, often marked by turning points, seems to be the time at which a person becomes active to counteract oppressive factors. The person shows the resilience to try to understand the meaning of what has happened and to make a change. This could be regarded as an emancipation process. In analogy with the work of Paolo Freire (1970): A person becomes aware of oppression (and of injustice) and then tries to become 'literate' to be able to articulate personal experiences and to free him- or herself from suppressing factors. Sharing experiences with peers is a powerful form of support in this process. In this process, the person explores the nature of his or her disability. This often causes a struggle with the acceptance of the vulnerability and finding ways of managing the disability.

The tenet of vulnerability seeks to understand and to support the person in this process. From the narratives it is shown that people appreciate the support of professionals in both the exploration of the *history* of the vulnerability and the exploration of how *to handle* the

[36] Meininger (2002, p. 161) puts interdependence in the frame of professional care, stating that autonomy is always embedded in care, but that this "can only be understood on the basis of a careful attention for the values and conceptions of the persons who are involved in the care relationship". See also: Manschot (1994) and Roovers (2004).

disability as well as possible. With regard to the latter, a specific task is to assess the characteristics of the personal niche, the safety or comfort zone specifically adapted to the vulnerability of the person (see chapters 3 and 4). A well-developed personal niche will be an integrated part of the identity. In the narratives it is seen that once people find their niche and are able to exert control, this is regarded as personal empowerment. People are proud that they have succeeded in 'surviving' and 'managing'. Hence, vulnerability is not something to avoid or to be afraid of, but contributes to the unique identity and strengths of the person. It becomes a form of life art to take care of it. Consequently, the notion of the personal niche should be connected to the notion of autonomy. When the person is able to take care of the vulnerability, this enables him or her to direct the own life. This does not mean that the vulnerability is gone, but that the person is reasonably able, with the help of external resources, to live with it and maintain a certain balance, which allows him or her room to use his or her capacities. Interdependence with regard to the personal niche is the dependence on external resources, such as personal support, medication and other aids (e.g. adapted housing arrangements, household services and meal supplies). The environment should provide the person with the resources to enable him or her to have a desired personal concept of autonomy. A well-functioning personal niche forms a basis for autonomy and social participation.

For professionals, vulnerability (in terms of an illness, a disability or a problematic situation) will often be the cause of engagement with a person. Sometimes needs with regard to vulnerability ought to be addressed immediately. A person needs protection or immediate treatment. Good care will however go beyond this. It will pay attention to the different dimensions associated with vulnerability, such as the subjective experiences that determine the perspective of the person, the desire to understand the (cause and meaning of the) vulnerability and the desire to find adequate ways to take care of it. By understanding, the vulnerability can obtain a place in the personal identity. Finally, someone always searches for the social consequences of a disability, the meaning with regard to the position in the world.

Baart (2007) adds another dimension of vulnerability. He states that vulnerability also offers the chance for solidarity and that it is also connected to standards for good care. An important task of the professional is to connect to the vulnerability of the person, in a way that the vulnerability is respected and neither denied nor transformed into technical jargon. The professional is offered a chance of solidarity with the person in his or her personal struggle. Vulnerability should be understood in terms of its complexity, meaning, value and precariousness. This requires moral compassion and often persistent efforts to understand what the vulnerability is about.

Vulnerability and identity

In both Baart's (2001) and my study, autonomy is found in the affirmation of a self who has struggled (or is still struggling) with the disease, but is proving to be able to live a 'normal life' *with* the illness or disability. In the course of a recovery process, the personal vulnerability is at a certain moment in time often even regarded as something valuable, because it has offered the individual valuable and unique experiences. The uniqueness of these experiences contributes to identity. Being able to overcome certain consequences of the vulnerability reinforces autonomy.

The American philosopher Schneewind (1999) points out that autonomy is primarily an emancipatory notion. People feel hindered by other people or circumstances that have a grip on them and want to get rid of it. Hence, the primary meaning of autonomy is not self-reliance or self-determination. It implies a struggle to get oneself free from hindering forces. We recognize this in the stories about recovery in chapters 2 and 3. In many stories first freeing oneself from oppressing forces comes to the for, only in a later phase followed by a strive for self-reliance and self-development.

Vosman (2007) connects the notion of autonomy to the position of caregivers, who have to decide what to do in situations in which a person is not able to express him- or herself, such as people with dementia. The caregiver has to be aware of the intentions of his or her interventions. He or she should also distinguish between his or her position or intention and the goal. A moral intention might be demarginalisation. Central questions that should be asked, is: Can I as a caregiver connect the intention of my actions to the person in front of me? What does he want to move away from, and where does he want to go to? (compare also Timmermann, 2010).

Vosman refers to the French philosopher Ricoeur, who wrote about the relationship between autonomy and vulnerability. Ricoeur says that vulnerability implies 'carrying' autonomy. First, there is 'fragility' or frailty. A human being is in all respects touchable; this carries autonomy. This also means that autonomy cannot be placed above vulnerability, because vulnerability is its carrier. It is not possible to cast judgement from the perspective of autonomy about vulnerability. Vulnerability constitutes autonomy as human autonomy: it is acceptable that one makes one's own decisions, but on the basis of the fact that one is constantly vulnerable. This point of view means that all humans are constantly subject to what is happening to them and around them. Professionals and care recipients are equal here; both have to experience in a passive way what is happening. Human beings are acting, responsible and accountable people against the background of passiveness, which Ricoeur calls "passable". Ricoeur states that ability[37] is only possible if you become aware of the fact that you are at the same time constantly vulnerable. Autonomy then becomes a notion of interdependence (cited by Vosman, 2007, p. 9).

Baart (2007b) underlines the difference between being touchable and being vulnerable. The basic layer is frailty, touchable-ness, 'fragility'. Vulnerability floats on this layer like a boat. This means that human beings are constantly fragile, but at some specific points they are vulnerable. The degree of vulnerability varies from individual to individual.

[37] The French word is "pouvoir", which means both being able and having power or strengths.

On top of fragility and vulnerability are autonomy and different forms of abilities and strengths. These do not only become public through expressions of the will, but also, for instance, more indirectly through stories. For example, it is a form of ability to be able to indicate 'this is what is important to me in my life'. This expression is a form of autonomy. This hierarchy is visualised in the next figure.

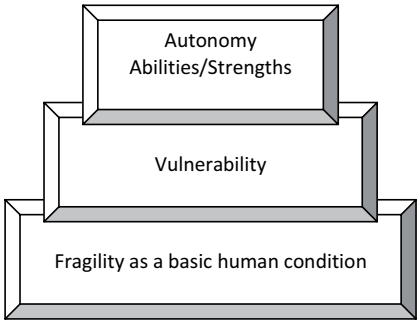


Figure 5.2: A hierarchy of fragility, vulnerability and autonomy (Baart, 2007b)

These insights are valuable to the notion of reciprocity because from both sides, from the sides of the professional and the recipient, fragility is a shared human condition (and a basis for solidarity). The shared assumption is that every person has different forms of vulnerability, abilities and strengths, and, in addition, strives for autonomy.

Finally, it is important to note that in each situation the way in which autonomy is perceived by the individual has to be explored. From the narratives it becomes clear that the way in which independence and autonomy are conceived differs from person to person. Not only might one conception of autonomy be rather different from another conception, but also an individual conception of autonomy might consist of different aspects. Shakespeare (2006) points, for example, to the fact that some people consider safety and a steady living arrangement so important that they do not value independence at this point.

Autonomy and social participation

A third aspect of autonomy, after vulnerability and identity, is related to the notions of social participation and social inclusion. Social participation refers to engagement in social contexts such as the neighbourhood, family, work, education and recreation. It refers to the fulfilment of meaningful social roles.

In this study, but also in many other qualitative studies,[38] the issue of social exclusion because of an illness, disability or poverty is prominently present. Marginalisation, stigmatisation and discrimination are experienced in the domains of social relations, housing, social security, health care, employment and education. At the same time, the studies show that people, like all human beings, have a strong desire to belong to a

[38] To mention but a few of these studies: Baart, 2001; Baart, 2002; Dunn, 1999; Hoogenboezem, 2003; Huxley and Thornicroft, 2003; Kröber, 2008; Kwekkeboom, 2001; Nuy, 1998; Sayce, 2002; Van Doorn, 2002, Wolf, 2002).

community, not only because they depend on resources provided by a community, but also because they want to contribute to it. Being part of a human community as an autonomous individual, experiencing love, rights and solidarity, is essential for recovery, health and wellbeing.

Disability is a result of individual impairments, personal attitudes and physical and social structures. A key dimension of disability is the extent to which a society removes barriers and enables people to participate, regardless of their individual differences. This relates to social *inclusion*. Social inclusion may be defined as the product of the willingness of an individual to contribute to social contexts and the accessibility and acceptance of a social environment.[39]

Bates, Miller and Taylor (2002) define social inclusion in terms of three aspects: access, a decent standard of living and relationships. Social inclusion concerns access to resources, decision making and jobs. A decent standard of living refers to a good standard of health and housing, the development of skills and abilities, income and living in safety. Inclusion in terms of relationships refers to engaging in friendships and social networks.

Schalock and Verdugo (2002) project social inclusion (for people with disabilities) onto a macro-, meso- and micro-level. On the micro-level, people have accepted social roles, for example by being a neighbour, volunteer, classmate or colleague. On a meso-level, people experience social acceptance and appreciation for the roles they fulfil. On a macro-level, the government ensures that laws and regulations are focused on inclusion and increasing the chances and opportunities of people with limitations in this respect.

Social inclusion concerns making sure that all human beings are able to participate as valued, respected and contributing members of society. It is, therefore, a normative (value-based) concept – a way of raising the bar and understanding where one wants to be and how to get there. Social inclusion reflects a proactive, human development approach to social wellbeing that calls for more than the removal of barriers or risks. It requires investments and action to bring about the right conditions. Recognising the importance of difference and diversity is important. However, social inclusion goes one step further: It calls for the validation and recognition of *diversity* as well as recognition of the *commonality* of lived experiences and the *shared aspirations* among people. This strongly suggests that social inclusion extends beyond bringing the 'outsiders' in, or notions of the periphery versus the centre. It is about closing physical, social and economic distances that separate people, rather than only about eliminating boundaries or barriers between *us* and *them*.

Saloojee (2003) has identified five critical conditions for social inclusion:

1. Valued recognition: conferring recognition and respect on individuals and groups. This includes recognising the differences in development and, therefore, not equating disability with pathology; supporting community initiatives that are sensitive to cultural and other differences; and extending the notion to recognising common worth through specific programmes such as health care.

[39] In paragraph 5.5.3, I discuss the notion of social inclusion from the perspective of the community or society, adding remarks about some dangers of forced or inappropriate social inclusion.

2. Human development: nurturing the talents, skills, capacities and choices of people to live a life they value and to make a contribution both they and others find worthwhile.
3. Involvement and engagement: having the right and the necessary support to make/be involved in decisions affecting oneself, family and community, and to be engaged in community life.
4. Proximity: sharing physical and social spaces to provide opportunities for interaction, if desired, and to reduce social distances between people. This includes shared public spaces such as parks and libraries; mixed-income neighbourhoods; and integrated schools and classrooms. I would include here the notion of the social niche (paragraph 3.9), which can be considered an intermediate space for offering opportunities for social participation.
5. Material wellbeing: having the material resources to allow people to participate fully in community life. This includes being safely and securely housed and having an adequate income.[40]

5.4.6 The tenet of empowerment

I have discussed the tenet of autonomy from the angle of an increasing capacity to take care of the vulnerability, the development of an autonomous identity and increasing social participation. All these forms of increasing autonomy can be regarded from the notion of *empowerment*. I will now connect insights from theories on empowerment to these angles. The tenet of empowerment in terms of the professional refers to helping the person to empower him- or herself.

A good understanding of concepts of power, within the caring relationship, in the life world of the person and in society will help to be aware of mechanisms of power not only within the relationship, but also in the individual and the community. Sometimes the professional faces situations of powerlessness, in which empowerment seems not to be in the foreground. Here, working according to the tenet of presence, and just being with the person and offering comfort, is the main issue at stake.

As far as the (powers of) systemic contexts of institutions and society are concerned, the professional also finds him- or herself in a double position. On the one hand, he or she has to relate to systems from the perspective of the client. On the other hand, he or she has to relate from the own perspective to the same systems. Working in this double triangle requires constant reflection and deliberation. Moral values play a guiding role here. Deliberation between the powers and requirements of formal systems and the interest of the client should take place on a continuous basis. It is a trade-off between possibilities and impossibilities, and a deliberation which actions can effectively serve people in unable circumstances.

[40] A study by Kröber (2008) confirms the importance of the conditions mentioned here. His object of study was how organisations providing professional care can be more focused on social inclusion. According to his findings, organisations that were strongly focused on social inclusion paid a lot of attention to the preferences and possibilities of the clients. They actively worked on creating safe places in the community with valuable social networks, in which people could develop themselves and make a positive contribution. Professionals were not only client-centred but also community-oriented (and were allowed by management to provide both personal and community support). A strong negative factor proved to be a long institutional history.

Taking care of power imbalance

The professionals in the narratives seem to operate cautiously in order to keep a power balance.[41] They put the other as much as possible in the directing position. These professionals are aware of the fact that they start on an unequal power field. They should be conscious of their *power base* (knowledge and personal and professional competences, access to financial means, information and people in charge). Within the relationship between professional and client, the professionals can use these powers to the benefit of the other, but if they want to strengthen the other, these means have to be allocated in such a way that the other is given the opportunity to use these resources in his or her personal development or empowerment process. This can also be phrased as using *power to*, which is the ability to initiate a movement or transformation (Miller, 1991b).

Good care includes being aware of the differences in terms of position and power. Regardless of other differences that might contribute to the powers of the professional, two aspects are always present. The first is that the professional *role* as it traditionally is conceived places the professional in a situation of direction and control. This role is connected to professional *status*. The second aspect is that the client usually starts off from a vulnerable position. Seeking help is associated with needs connected to vulnerability, and the incapacity to solve problems. The beginning of the relationship is therefore marked by an antithesis between strong and weak, between powerful and powerlessness.

Good care is aimed at equalising the power balance (Miller and Stiver, 1997). The aim is to decrease inequality in the course of the relationship. In the dialogue between professional and client, issues of power and powerlessness should be acknowledged and used in an empowering way. There might be disagreements, but through dialogue these are discussed and put into perspective.[42] The relationship that develops in the interpersonal space should provide the client with opportunities to become stronger and more powerful. Powers should be recognised and made visible, correctable and developable. In the discourse on good care it is important that the strengths of the other can appear. The formal framework (e.g. the influence of organisational rules, juridical measures or legislation) also has to be considered. Systemic powers might be in the way of personal development, powers that might be out of reach of both professional and client. Joining forces might help to acknowledge this power field and to find ways to deal with it.[43]

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[41] I follow here the Weberian conception of power, in which rational-legal authority is anchored in impersonal rules that have been legally established. In case of a professional his legal authority or status is endowed by the institution he is working for and the professional group he belongs to.

[42] At the start of relationships, it is conceivable that the client tries to use the professional in a manipulating way. Heyndrickx *et al*. (2005, p. 58) ascribe this to "deficits in connection" caused for example by negative experiences during childhood that have disturbed the normal process of attachment and individuation. This can result in relational problems, such as a lack of connections (shutting oneself off), an excessive connection (claiming or suffocating behaviour) or a pathological connection (imbalance between individuation and connectedness expressed by simultaneously attracting and rejecting the other). Working with people who are seriously disabled by a basic lack of self-connection requires special efforts from the professional to shape the interpersonal space in such a way that a basic sense of trust can be restored.

[43] The power balance is severely disturbed if rights are denied and a person suffers from discrimination or other kinds of oppression. Thompson (1993) states that the professional, being aware of mechanisms of oppression,
- recognises the socio-political context of service users' life experiences, and of the agency's role and function in that context;
- aims to ensure that the ways in which services are provided do not contribute to oppression; and

I would also like to use power balance in another way, namely as a complementary notion. The strengths of the professional complement the strengths of the person. Constructive powers (in the sense of qualities, possibilities and available resources) are articulated. Powers are not used for purposes of competition or control, but for mutual development. The action of having power *over* is replaced by the idea of power *with*. The *power with* or mutual power model makes the development of empowering relationships central (Freedberg, 2009; Surrey, 1987). Power *with* others means that both parties get stronger through the relationship. The relationship then works to sustain mutual empathy and interest, which does not involve winning or losing but rather a commitment to strengthen the connection. The notion of partnership can help to regulate the process of redistributing power and increasing personal strengths. Within the 'community' of professional, client and others, everybody's talents and possibilities can be used. Power is not something that is a given fact, but an *expanding commodity*, something that, conform the notion of *power with,* is developed in the collaboration between different parties (Israel, Checkoway, Schultz & Zimmerman, 1994).

Box 5.3 Notions of empowerment

In the past two decades, the notion of empowerment reappears over and over again in social theories, although worded differently and used in different contexts. Examples are found in theories on social participation (Van Regenmortel, 2008b) and health promotion (Jacobs *et al*., 2005).

Peterson and Zimmerman (2004, p. 129) give the following definition of empowerment: "Empowerment is an active, participatory process through which individuals, organizations, and communities gain greater control, efficacy, and social justice". They include the notions of active participation and social justice in their definition. Van Regenmortel (2008, p. 22) describes empowerment as "[a] process of reinforcement in which individuals, organisations and communities get a grip on the own situation and their environment, via acquiring control, sharpening critical awareness and promoting participation". She also adds the notion of critical awareness.

At an individual level, the definition of Mechanic (1991, cited in Zimmerman, 2000, p. 43), very closely reflects a recovery process: "Empowerment may be seen as a process where individuals learn to see a closer correspondence between their goals and a sense of how to achieve them, and a relationship between their efforts and life outcomes". So does a definition given by Solomon (1976, p. 6): "Empowerment refers to a process whereby persons who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skills in the exercise of interpersonal influence and the performance of valued social roles".

- aims to assist users in their struggles against oppression.

Zimmerman (1998) formulates three central themes: control, critical awareness and participation. These themes are mutually intertwined. The themes can be recognised in recovery and rehabilitation. Getting control over symptoms, becoming aware of the own situation and reparticipating in social life are essential aspects. There is a striking parallel with mechanisms of oppression and poverty. A (total) lack of control of the own situation and feelings of powerlessness, is common both for poverty and severe mental illness.[44]

Simon (1994) describes the promotion of critical awareness as an approach that 'contextualises' individual experiences and suffering and consequently decreases self-reproach. At the same time, the person gets more insight into the nature and the impact of own choices and may take responsibility for them. Critical awareness forms a bridge to action and participation.

Helping the person to empower him- or herself

The tenet of empowerment is to be empowering to the person. Jacobs, Braakman and Houweling (2005) warn that empowerment must not be considered as a professional intervention. Empowerment (like recovery) is a process of the people themselves. A professional can be empowering but cannot instil empowerment. The professional has to be empowering in a way that leaves the person with plenty of space to react. Whether the person responds and how he responds is up to the person him- or herself. This is inherent to the notion of care responsiveness. I subscribe to the idea of Labonte, who states that empowerment "exists only as a relational act of power taken and given in the same instance" (Labonte, 1994, p. 256).

Good care is aimed at making the person stronger. I conceive this in a broad sense. In chapters 2 and 3, many different forms of becoming stronger came forward. Stronger may refer to gaining health, coping better with the illness or increasing self-confidence and social skills. The role and contribution of professional care may differ, but a common orientation can be characterised in the following aspects. The first is that the professional not only looks at deficits and problems, but also at positive aspects, such as the person's abilities and lessons learned from experiences (good and bad). The second is that the professional uses encouraging communication. He articulates the values that he observes. He encourages the person to use personal strengths. The third aspect is that in the actions of the professional there are always strengthening elements. The professional's actions are aimed at reinforcing the client, either directly or indirectly, by creating facilitating resources.

Good care is aimed at and, whenever possible, contributes to empowerment. Therefore, theoretical notions of empowerment are part of the discourse on good care. Empowerment is a central notion in recovery stories (Boevink, 2009; Boevink, Plooy & Van Rooijen, 2006; Fisher, 1994) as well as in psychosocial rehabilitation models (Anthony *et al*., 2002; Rapp & Gosha, 2006; Wilken & Den Hollander, 2005). From this study it becomes clear that there is a strong relationship with the tenets of recognition, autonomy and vulnerability.

[44] Compare the 'learned helplessness' theory of Seligman (1975), theories on powerlessness and alienation of Seeman and others (e.g. Seeman, 1959; Finifter, 1973; Gaventa, 1980; Mann, 1986), and the 'locus of control' theories of Rotter (1990) and Lefcourt (1976; 1984).

Autonomy, relation and diversity

Gaby Jacobs (2001) has analysed the notion of empowerment in the light of feministic care. She derives three underlying paradigms from the empowerment notion: an autonomy paradigm, a relation paradigm and a diversity paradigm. I use her notions because they connect the tenet of empowerment to the other tenets.

Jacobs considers autonomy as a tenet of social power. The care demands of clients are put in a societal context, whereby unequal power relations are included in the perspective. Existing power relations may lead to impediments to having direction over the own life. In this paradigm, empowerment can be considered a process of self-determination. For the care discourse, this means that the acting of professionals is characterised by a politicising way of working. Professionals should mobilise clients to take their life in their own hands and help to equip them with the needed skills and resources. In the relationship they should try to avoid unnecessary use of power and should encourage people to bring about changes by themselves by using their own wisdom and strengths.

In the relation paradigm, empowerment is considered a mutual relational process of self-development. This is characterised by five components: vitality, an increasing desire for connectedness, an increase of self-esteem, an increase of self-understanding, and the development of relational abilities such as empathy and responsiveness. Professionals should use their own relational means to create mutual developing (empowering) relationships, which in turn can lead to transformations in the relation with the community.

In the third paradigm, diversity, empowerment can be regarded as "processes of embodied and narrative self-construction" (`Jacobs, 2001, p. 23). Jacobs refers here to processes of identity (trans)formation. In feministic care, multiple explanation models are used to explain problems and complaints of women. According to this view, problems of women arise if they try to avoid or dissolve tension and contradictions in themselves by giving up specific aspects of their self. The paradigm keeps open a diversity of perspectives, values and manners. Professionals should address the power position and desire of clients, but should also realise the risk of exclusion and oppression from the part of society. When connecting empowerment to the tenet of diversity, it requires from the professional the courage to take an intermediate position between the 'strangeness' of the other and the perspective of society. An empowering approach is focused on helping the other to reinforce his or her identity (and the related self-esteem and self-confidence).

Insurgent empowerment

From the narratives studied in Chapter 3, a specific form of empowerment comes to the fore. I would like to call this *'insurgent empowerment'*. This is a form of personal empowerment that is a reaction to extreme oppressive circumstances, such as being locked up in an isolation room. The oppressive circumstances call upon a surprisingly strong counter power. Participants indicated that they were surprised that they possessed this power. It was a power that had apparently been present in the person and was spontaneously released. In retrospective, many participants considered this a turning point, or a first step in their recovery process. Since the awareness comes retrospectively, this power can also be considered a form of pre-empowerment.

Box 5.4 Aspects of empowerment

Levels

Empowerment consists of three levels: the psychological or individual level, the organisational level and the community level (Vandenbempt, 2001). These levels are mutually related and interdependent. Working on empowerment on one level contributes to empowerment on other levels. Psychological empowerment integrates perceptions of personal control, a proactive approach to life and a critical understanding of the social environment. On this personal level, one tries to *get hold of the own life*, in a (more) conscious and (more) critical way. It also involves giving attention to the own social networks and attribution of meaningfulness. Empowerment on an organisational level entails processes and structures that increase one's skills and develops the mutual support that is necessary to bring about change on an individual, group or community level. The notions of emancipation and participation are central on this level. On the level of the community, empowerment refers to people who work together in an organised way to improve and maintain their quality of life (collective empowerment).

Process and outcome

It is useful to distinguish empowering processes from empowered outcomes. The former refers to the way people, organisations and communities become empowered, while the latter refers to the results of these processes. Empowering processes are created by people themselves, but can be facilitated by others who provide or create opportunities. An empowering process can be conceived as a series of experiences by which individuals (re)discover their strengths and identity, and achieve a tighter connection between their goals and how to reach these. It can also include gaining better access to and control over resources. In empowerment as process, there is an emphasis on the cyclical and spiral-shaped character and on elements like co-operation between different people, growing consciousness and the development of skills. It concerns all the elements that contribute to the process of control and gaining influence on the own life: "Empowering processes are those where people create or are given opportunities to control their own destiny and influence the decisions that affect their lives" (Zimmerman, 1995, p. 583).

On an individual level, results can be expressed in the degree to which people have become stronger. It concerns the situation-specific perceived control and competences, the critical consciousness and the interactions that result in individual or collective actions.[45]

[45] On the level of the organisation, the following aspects can be outcomes: the presence of organisational networks, the effective mobilisation of sources to reach goals and policy influence. The results on a community level can be, among other things, access to resources and facilities in the community, the chances of the local population to participate in the community and the presence of organisational coalitions.

Personal empowerment

Personal empowerment (also called psychological empowerment) consists of three aspects: an intrapersonal component, an interpersonal component and a behavioural component (Zimmerman, 1995; Zimmerman, Israel, Schultz & Checkoway, 1992).

The *intrapersonal* component is related to the way people conceive themselves: the belief in own abilities, the belief that one can influence one's own life and the environment and also the will or motivation to do this. This is summarised in the psychological notions of perceived control, self-efficacy, motivation to control, and perceived competence and mastery.

The *interpersonal* component refers to the interaction between people and their environment, which make it possible to successfully influence social and political systems. This component consists of critical awareness of possibilities, prevailing values and norms and needed means to realise goals, as well as the skills to use these possibilities and resources. Apart from awareness, this requires the acquisition of skills, such as decision-making and problem-solving skills.

The *behavioural* component refers to specific actions that are aimed at influencing the social environment by means of participation, for example in self-help groups, associations and cultural or religious networks (*capacity building)*.

The components are described in terms of outcomes, but they also refer to a process: developing self-confidence, skills, acquiring resources, working together with others and exerting influence (Zimmerman, 2000). One component neither necessarily leads to another, nor is there any hierarchical order.

Not every person will be able to attain (all) the abilities mentioned above, for example because of the nature of the disease or the disabilities. Still, from the analysis of the narratives it becomes clear that in a process of recovery, elements of intrapersonal empowerment, for example in developing mastery over the personal niche, but also elements of the other components are realised, also by people with more severe disabilities. An important step in this process is that people become agents of their own life. This always happens in mutual interaction with others: empowerment is supported by empowering support.

Resilience

A related notion is *resilience*. Resilience is defined as a dynamic process in which individuals exhibit positive behavioural adaptation when they encounter significant adversity or trauma (Luthar & Cicchetti, 2000; Luthar, Cicchetti & Bekker, 2000). Resilience is a two-dimensional construct concerning on the one hand the exposure of adversity and on the other hand the positive adjustment outcomes of that adversity.

Ridgway (2004) conducted a study to connect the notions of recovery and resilience and concludes that these are two sides of a multi-faceted phenomenon. She notes that many people who are faced with adversity due to psychiatric disability and psychiatric hospitalisation are able to "adapt, cope, rebound, withstand, grow, survive, and define a new sense of self" (cited in Deegan, 2005, p. 29). Deegan states the following in this regard: "The capacity for resilience does not end when one is diagnosed with a major mental disorder. Rather, those with psychiatric disabilities can be viewed as resilient even when

struggling to recover from psychiatric disorder" (2005, p. 29). Driessens and Van Regenmortel (2006; 2008) have formulated a number of constructing elements of resilience that professionals can support. These include abandoning the victim role, transforming a negative identity into a positive identity (including increasing self-respect) and emphasising the power of 'giving' in reciprocal relationships.

Empowerment and vulnerability

A specific form of personal empowerment in relation to vulnerability is the development of the *personal niche*. By learning to take care of the specific sensitivity for factors that can disturb the balance and re-evoke the illness, people get more power over their own body and mind.

On an interactional level, empowerment sometimes seems to be a notion contradictory to the reality of people whose life is signed by multiple and continuing problems, such as the people whose narratives I reported in Chapter 3, the homeless described by Nuy (1998), Van Doorn (2002) and Hoogenboezem (2003), the people living in deprived neighbourhoods described by Baart (2001) and the 'new poor' featuring in the book of Heyndrickx *et al*. (2005). Their situation is often determined by extreme feelings of powerlessness. In addition, they seem to lack the psychological and communicational powers to reconnect to the world, a world that has in many cases for a long time humiliated them and refused them access to facilities and resources, causing deep distrust (Driessens & Van Regenmortel, 1996). Heyndrickx *et al*. (2005) speak of people who have endured 'multiple hurt'. They define this as follows: "Someone is hurt if the reliability of existential and meaningful relationships is fundamentally damaged. By this the basic trust in himself and the surrounding world is affected. Multiple refers to the enduring and mutual effects on the connections with the self, the other, the community and time' (Heyndrickx *et al*., 2005, p. 55).

In theories on empowerment vulnerability not only has an individual dimension but also an institutional and structural dimension (Driessens & Van Regenmortel, 2006, 35–36). All these dimensions should be taken into account. For example, disrespect from the side of society for people who have a disability and/or are living in poverty (these are often related) is a huge barrier to self-development (Sennet, 2003). By denying people access to social participation, the possibilities of development, recognition and autonomy are limited.

An empowering practice

In summary, the tenet of empowerment provides professional practice with a framework to understand better issues of power and power differences. It helps to understand the complex interaction between human agency and social systems. It helps to find ways to strengthen the person and to help the person to become stronger. It helps the professional to be aware of his or her own 'power base' and to make use of his or her potentials in a careful way, respecting both the vulnerability and the existing strengths of the person.

In the tenet of empowerment the huge gap between people in a vulnerable position, the position of the professional and the reality of society must be bridged. An empowering approach can only be successful if these positions are known and recognised.

As far as the person is concerned, it starts with a double recognition. The first recognition is the recognition of the vulnerability and the hurt. The second recognition is the presence of what Van Regenmortel (2002, p. 192) calls “psychological capital”. This capital rests on pride and self-esteem and on the intrinsic power to live a dignified life despite the situation. By this shared recognition, a professional can lay a foundation to help the other in his or her re-connection process.

In the restoration of human integrity and human dignity, recognition of personal capital is essential. Within the personal-professional relationship, opportunities are taken to reinforce the person and his or her identity and capacities. The tenet of empowerment concerns how people can be reconnected to their self and their narrative (the personal resources), a personal niche, the community and society (social resources). Good care is aimed at helping the person in these (re)connection processes.

Personal empowerment starts with the articulation of current strengths. An empowering approach on the one hand makes an appeal to these strengths and on the other hand offers possibilities to use and develop strengths in (non-rejecting and trusting) relations with others. Strengthening may refer to a wide array of aspects that are related to fundamental aspects of recognition (self-confidence, self-esteem and self-respect), vulnerability (social skills, coping and resilience), and increasing participation in and contribution to social networks. In the tenet of empowerment, three aspects to increasing mastery are present: increasing control, developing critical awareness about the own situation and identity, and social participation.

Another aspect of an empowering approach is to help the person to connect to ‘empowering environments’ in the community. The tenet of empowerment requires that good care is not only aimed at an individual level, but also at an organisational and a community level. Empowering care also includes the creation of social niches and gaining better access to and control over resources. Professionals can function as intermediaries or bridges in this regard.

5.5 Objectives

After discussing the ethical foundation and the six tenets, I now examine the ultimate objectives of good care. I approach this from three angles: the recipient of care, the professional, and the community (or, in a broader sense, society). In the next table the objectives of care are listed.

Table 5.3: Objectives of good care

2. Objectives	
2.1 The care receiver (paragraph 5.5.1)	*The ultimate aims of good care, seen from the perspective of care recipients*
	Goods realised in the practice
	Goods realised by (as a result of) the practice
2.2 The professional and his practice (paragraph 5.5.2)	*The ultimate aims of good care, seen from the perspective of care providers*
	Social
	Physical and psychological
	Existential
2.3 The society (paragraph 5.5.3)	*The ultimate aims of good care, seen from the perspective of society*
	Social-political

These objectives are developed on the basis of an analysis of the (desired) goods prevailing in the narratives. This means that other types of goods or objectives of potential importance are not appearing.

I have chosen not to elaborate on the organisational context of care provision. I wanted to remain close to the angle of the perspective of care recipients, who in their narratives mainly speak about their experiences with caregivers. However, the institutional context certainly comes to the fore in the stories. It can be regarded as a context that facilitates or hinders the professionals working in that context in their provision of care to clients. The elements of discourse, finality and position, can – and should – be translated into a 'caring organisation', which is constructed on the basis of the principles and aims of good care. The organisation where the professional works is extremely important to realise the objectives described in paragraphs 5.5.1 and 5.5.2. It creates the culture and conditions that make good care possible. The way care institutions operate is also embedded in a social-political context, following the objectives described in paragraph 5.5.3.

5.5.1 The care recipient

What are the ultimate aims of good care, seen from the perspective of the recipient?
I would like to use here the notion of goods, as described by MacIntyre (1985) and Ricoeur (1992). MacIntyre (1985) claims that practices make the achievement of goods internal to them possible. In contrast to what he calls external goods, for example money, status and

prestige, internal goods are not objects of competition and can be recognised as goods, and realised only by those who fully participate in the practice. He follows the Aristotelian line of thinking: A practice should be good, even excellent, not only in the act of practicing itself, but also in terms of the goods that are realised in and by the practice. The word 'goods' does not refer here to merely something material (such as a piece of furniture, or a problem being fixed), but to a quality or 'bonum', something that does well to the person. I distinguish between two types of goods: the goods that are realised *in* the practice and the goods that are realised *as an external effect of* the practice, which are a result of it, i.e. an outcome. Of course, these goods are also interconnected. Goods realised *in* the practice can produce goods as an outcome of the practice. The goods realised in and as a result of the practice contribute to the development of personal identity and autonomy.

In the next table the different goods appearing in the narratives are listed and then explained.

Table 5.4: Goods realised from the perspective of the recipient

2. Objectives	
2.1 The ultimate aims of good care, seen from the perspective of the recipient	
Goods realised in the practice	• To be allowed to be different and to belong • To feel safe (respect for the personal niche) • To be recognised and affirmed (recognition, experiencing love, respect and esteem)
Goods as an external effect of the practice	• Handling vulnerability (better, or being able to live with it) • Becoming stronger; experiencing improved wellbeing (strengthening personal identity and autonomy, experiencing own strengths and value) • Increased social participation (meaningful social roles, activities, citizenship)

Goods realised in the practice

The first good realised in the practice is to be *allowed to be different* and at the same time *to belong to* the community of humanity. The aspects that are different (in the case of care situations: the disorder, the disability, a behaviour that is strange compared to average or 'normal' behaviour) are not stashed away. But also, if they are the focus of the professional (which is obviously the case when there is a demand for care), they are not separated from the rest of the entity of the person. A person is not treated as a diagnosis, but as a person. The person, his problems and needs are not separated from the context. The connection to the natural environment, such as family or the neighbourhood, remains visible. Thereby the person does not experience (further) separation or alienation, but stays in connection with other parts of existence.

The second good is *to feel safe*. In all the stories, safety is experienced as a beneficial good. It is connected to confidence, trust and rest. The interpersonal space provides safety by respecting personal values and boundaries. It is related to respect for the personal niche. Another aspect of safety is to be sure of the availability and presence of a professional. It concerns the confidence not to be abandoned. Lastly, the professional also provides reassurance. The person is assured (again) of the support and protection of the professional. In case of anxiety and insecurity, the professional is there to provide assistance.

The third good realised in the practice is *to be recognised and affirmed*. This corresponds to the basic need of recognition, in which love, respect and esteem are experienced (Honneth, 1995). The person experiences that he or she is *seen*, in his or her uniqueness and suffering; seen both as a person with a disability and as a person with strengths; seen as a person with a history and a future. He or she is also seen as a fellow human being that belongs to the community. This is not only seen, but also acknowledged and *affirmed* by the professional. This good is often embedded in a form of companionship.

Goods realised as an external effect of the practice

As a result of the practice, goods that are realised are handling vulnerability, becoming stronger and increased social participation. Although there is a relationship between the three, they can also be considered separate yields.

The first good is handling vulnerability better or to be able to live with it. In many cases, vulnerability is a given fact, although not a static situation. The character of it may change over the course of time. There might be improvements or stabilisation. However, there is a huge difference between not being able to manage the vulnerability and being able to do so. A concept that has been developed on the basis of my analysis is the personal niche (Chapter 3, paragraph 3.11). Getting to know this personal space, which provides safety and certain equilibrium, and learning to (better) take care of it, is considered a valuable good.

Knowing how to handle the personal vulnerability is a part of becoming stronger and provides opportunities for social participation. One important aspect of the construction of a personal niche is that is accepted as a part of the identity. In the studies about recovery from severe mental illness, this is considered an important turning point. Two sub-goods appear here: the recognition of the own vulnerability, *and* the recognition that the vulnerability is simply a *part of* the identity, and not *the* identity.

'Becoming stronger' can become apparent in many different ways. It can be expressed in the development of self-confidence, self-respect and self-esteem (Honneth, 1995). It can be expressed in the development of skills, in the acquisition of knowledge, and in being able to keep a job. A better wellbeing is achieved and own strengths and value are experienced.

A third good realised by the practice is increased social participation. This can be expressed in terms of meaningful social roles and activities, but also in terms of citizenship. Citizenship stands for 'being part of the community', bearing equal rights, using public facilities like any other citizen. Social participation is not only the affirmation of the strengths as experienced by the person him- or herself, but also as experienced by society (see paragraph 5.5.3).

All goods contribute to the formation of identity and autonomy. In paragraph 5.5.3, I also connect identity to the societal good of social inclusion.

5.5.2 The professional and his practice

What are the ultimate aims of good care, seen from the perspective of the provision of professional care and support? Three types of goods can be distinguished, namely physical and psychological goods, social goods and existential goods.

In Table 5.5, an overview is given of the different types of objectives and the elements belonging to each type. Then these elements will be explained.

Table 5.5: Goods realised from the perspective of the profession

2. Objectives	
2.2 The ultimate aims of good care, seen from the perspective of the provision of care and support	
Physical and psychological (paragraph 5.5.2.1)	• Security (offering safety, being reachable) • Encouragement/hope • Increasing strengths
Social (paragraph 5.5.2.2)	• Companionship and attachment (not abandoning, continuing, allowed to attach) • Extending social participation
Existential (paragraph 5.5.2.3)	• Recognition and acknowledgement; revealing the value of the other • Comfort with regard to losses and suffering • Contributing to identity and autonomy

5.5.2.1 Physical and psychological goods

I have placed physical and psychological goods in one group to indicate that they are interconnected. Often in psychiatry, the mind is 'separated' from the body, thus contributing to the alienation of the person from the self. The participants in my study valued an integrative approach, in which physical as well as mental problems are taken into account. What needs special, or full attention, is the way physical and psychological phenomena are experienced. This is the validation of subjective experiences (Estroff, 1989; Strauss, 1989a;b; 1992; Wilken, 2006). This can in part also be regarded as an existential good.

Three types of goods were realised, namely security, encouragement and increasing strengths. All these goods are contextual by nature. They *may* realise in the context of the practice, but not per definition. People with a specific vulnerable disposition first of all need basic *security*. A professional should be able to address this need. This can be done by offering reassurance or protection or by letting the person attach him- or herself to the professional, but also by being faithful and by offering unconditional availability. It can also

be provided by offering a social niche, a concept developed in paragraph 3.9. Besides a psychological environment, a social niche is also a *physical* environment.

Encouragement can be a form of comfort, but can also be a mild form of empowerment. From the stories on recovery it appeared that encouragement and inducing hope are considered valuable goods. Encouragement provides the courage to go on, or to find new perspectives. Encouragement can also be established by a particular environment, event or experience. Positive experiences can be encouraging. Encouragement is an important part of the care process. Being empowering is a form of support for personal development and the achievement of greater autonomy and social participation. Although problems and suffering are recognised and affirmed, there is always a focus on finding solutions to problems and to make improvements.

Another good of good care is that it *strengthens* the person. This refers to physical, mental or social abilities. In practice, there is an emphasis on the own strengths and the own actions of the other. An appeal is made to the healthy side, i.e. the abilities and talents. By making this empowering appeal, these strengths are brought forward. Through this process, self-confidence, knowledge and skills as well as personal status can be increased. Strengthening might also be aimed at social networks, in the sense of increasing their support capacity or making them more accessible. In addition, a future perspective can be strengthened, for example by helping the person to find new purposeful directions and to set goals pertaining to ambitions and desires.

5.5.2.2 Social goods

Two main categories of social goods came to the fore. The first is companionship and attachment and the second is social participation.

Companionship and attachment

The interpersonal space is characterised by a feeling of togetherness, of *companionship*. There is a certain degree of intimacy, often caused by the act of trusting the professional by sharing with him or her personal information, and knowing that this information will not be misused. Companionship is a form of attachment that also contributes to safety. The person experiences a connection, a form of 'holding' (Winnicot, 1965). He or she experiences that he or she is not abandoned. This good is sustained through the continuing presence of the professional. This does not mean that a relationship never ends, but that as long as the professional is present in the life of the person, this is experienced as a 'close' and sympathetic relationship. By this act, the professional gives the other the opportunity to use the him or her as 'attachment' and a source of support and safety (see securing; paragraph 4.5). The basis for attachment is faithfulness, trust and confidence. Attachment may compensate for the lack of attachment experienced earlier in life. Attachment also provides a response to the basic need for belonging and recognition.

Companionship is associated with friendship. Care recipients in the narratives in Chapters 3 and 4 realised that it is not an ordinary friendship. I will discuss this notion in paragraph 6.1.2, writing about the professional on the metaphorical position of friendship.

In the rehabilitation literature, the phenomenon of 'befriending' is described. Different studies show positive effects, such as increased well-being and social functioning.[46] Often, companionship is arranged through voluntary work, as in the buddy model and 'befriending services' (Dean & Goodlad, 1998; Kal, 2001; Van Rooijen, 2005). The differences between a lay volunteer and a professional offering companionship are not clear. I suppose that although the experiences connected to companionship are not so different, the fact that companionship is offered inside a professional relationship makes a difference. In voluntary forms of companionship, there is 'only' the companionship. Although this is often accompanied by doing activities together, such as drinking a cup of coffee, going shopping or having a walk, these activities do not go beyond the activities themselves. Although there is the intention that companionship contributes to the wellbeing of the other, and indeed it does, there is neither (other) therapeutic intention nor does it fit in a long-term plan.

Extending social participation

Besides goods that are related to the care relationship itself and its goods in terms of personal recognition and taking care of vulnerability, good care is also aimed at helping a person to (re)connect to the world. Participation and re-integration are encouraged. A basic assumption here is that recognition in all its forms is only achieved through the social interaction with others. A meaningful life is connected to the meaning for others in the community in the form of social roles that bring meaning with them. Recovery and self-realisation can only be realised through social participation. This can also be placed in the context of citizenship. If possible, good care should be aimed at keeping or regaining full citizenship.[47] In the review in Chapter 2 and the narratives in Chapter 3, it is shown that 'longing to belong' to a community is considered an important aspect of quality of life. Professionals who do not only aim at the disability, but also at participation, contribute to the fulfilment of this need. Activities aimed at social participation can range from involving family members in treatment and having clients participating in peer support groups to getting housing and jobs. Activities can also be aimed at the community itself, in order to increase possibilities for participation (Kal, 2001; Rapp & Gosha, 2006; Repper & Perkins, 2003; Scholtens, 2007; Wilken, 2002). This can vary from giving information to other citizens and changing images about people with disabilities to fighting discrimination and stigmatisation (e.g. De Goei et al., 2005; Thornicroft, 2006).

Sometimes, an 'intermediary social space' is necessary, an in-between between the personal world, or the world of (mental) health care, and the public world, the society. This notion is elaborated on in terms of the social niche (paragraph 3.9). A social niche is an environment that serves as an ecological habitat and that provides resources that are adapted to the personal niche as well as resources that facilitate personal development and social participation. A special contribution is made by professionals who work in these social niches. The good that is realised here is a safe environment, which offers possibilities for recognition and development.

[46] See for example Harris, Brown and Robinson (1999 a; b), and Onrust & Smit (2005).
[47] Full citizenship implies being equal to other citizens, to contribute to the community, to enjoy rights that are fundamental to the community, and to be able to use resources that are available for everyone.

5.5.2.3 Existential goods

A third group of goods is those of an existential nature. I distinguish here between three aims: recognition and acknowledgement (revealing the value of the other), comfort with regard to losses and suffering and contributing to identity and autonomy.

Recognition and acknowledgement (revealing the value of the other)

In the discourse on good care, recognition plays an important role. In paragraph 5.4.4, I discussed Honneth's theory on recognition, which is connected to affirming, one of the five categories found in Chapter 4. Essential in the theory of recognition is that the value of a person as such is acknowledged and affirmed. In the thinking of Honneth, value is mostly connected to self-esteem. What makes someone special or unique is valuable. In my study I found that the revealing of personal value is an important aspect in recovery. Before arriving at affirming the value of the other, it should be articulated what this value is. Good care can be considered a search for values. Values should be discovered and revealed. Sometimes these values are hidden behind a curtain of indifference, covered by a severe depression or hidden behind vast poverty. In the narratives on recovery, self-trust, self-respect and self-esteem have often been severely damaged. Every contribution care and support can make to (a restoration of) these values, is important. Values can be divided into values belonging to the personal value system of a person and values belonging to a community or society.

I have stated that the value of human dignity is also a leading value in good care practices. On a personal level it should be explored which personal values constitute the human dignity of this person. This does not exclude the use of generalised human values or human rights as a basis for professional care. Yet, in every situation it should be explored anew how the value, or quality, of life is perceived and which values are at stake. These values can usually be found in ordinary daily life. In addition, articulation of a perspective should take place: what makes the person and his or her life valuable or worthwhile? This results in an understanding of what is threatened in the current situation and what kind of change is desired.

In the narratives a number of forms of how recognition was expressed by professionals became evident. These are related to trust, respect and esteem:

- expressing admiration for the way people have coped with difficult situations
- acknowledging what makes someone special
- admiring achievements and talents
- staying present with the person (in good and in bad times)
- respecting the frailty and the personal niche
- identifying with the burden of the impairment
- making special efforts to get something done
- revealing values by creating conditions in which talents or skills can be discovered
- trusting someone to be able to handle something on his or her own
- advocating for rights
- reflecting on the narrative and thereby supporting the other in constructing his or her identity
- accepting gifts of the person

In all communication, it is affirmed that the other is a valuable person, both for the professional and for the community. This is part of the intersubjective process and the

creation of a caring relationship. Although problems and suffering are also recognised, the focus is on the positive aspects through expressing the personal values of the other. The notion of solidarity can, in this discourse on good care, be connected to the personal engagement and commitment of the professional. Solidarity includes not only sharing concerns and interests, but also working together on a 'project': formulating goals aimed at recovery (personal niche) and social participation. Solidarity can also include advocacy: advocating for the rights of people when they are not able to do this all by themselves.

Comfort with regard to losses and suffering

The recognition of losses and suffering is part of the discourse on good care. Losses and suffering are part of everybody's life, because everybody is equally vulnerable. Acknowledging suffering is not a specific professional activity, but it is an indissoluble part of good care, since it is connected both to the identity of the person and to the (understanding of the) present situation. It is considered a great good by care recipients if 'the story can be told', if pain may exist and is not stashed away. Even if mental phenomena or physical complaints cannot be medically explained, this does not mean that they are not experienced. The way experiences are shaped is part of subjectivity (Baart, 2002).

In many cases, a disease or disability and the associated burden cannot be 'repaired'. In a medical discourse on care, repair or cure is sustained until every 'technical' possibility has been considered. In a social discourse on care, personal identity and autonomy, with its subjective conception of quality of life and of personal good, form the anchor point. Comforting means being responsive to emotional needs. Often these need are connected to a process of mourning, which in the phases of recovery, as pointed out in Chapter 2, is part of the reorientation phase.

In the theory of presence, much attention is given to the meaning of suffering, sorrow and comfort (Baart, 2001; Baart & Grypdonck, 2008). Baart describes suffering and sorrow as a thorough loss or as an enduring lack that is felt as an existential shortage or as an elongated and unaccomplished longing. A common reaction of care providers is to start fighting suffering, which comes down to an attempt to regain power. The aim is to compensate for the shortage. Comforting is then placed in this context, aiming at eliminating the emotional impact of suffering or even suffering itself. Baart is in favour of another type of comfort, namely a comfort that is aimed at helping the other to reach another, better relation to the suffering.

In most recovery narratives, comfort is hardly explicitly mentioned. It is more the attentive and understanding presence of the professional that is regarded as comforting or soothing. The 'only' thing they seem to do is to give room to the experiences of the person. In some narratives, people tell that professionals explicitly showed compassion; they are emotionally touched, which was valued by the people, because the professional showed him- or herself as a human being instead of someone who keeps emotions at distance (as an attribution to this professional role). The moral appeal of suffering is being addressed.

There is a difference between experiences of suffering in the past and those in the present. The latter include mostly an appeal to the professional to recognise and do something about it. Professionals then combine comfort with looking together for possibilities to relieve the stress associated with the burden.

Baart (2001) describes comforting as an offer of a way of seeing and being, which allows suffering instead of putting it (away) in, for instance, an explanatory framework of a diagnostic category. The first (seeing) consists of information, explanations and interpretations, helping to find meaning and so forth. The second (being) emphasises nearness, sociability, being touched, embraced and caressed. The experience of suffering is integrated into a relationship and not put apart. If the recipient accepts this twofold offer, there are two effects. The first effect of this combined approach is that the incarcerated sorrow is transferred to a larger unity. What is locked inside can come out. This often has a liberating effect. The sorrow also now has meaning or a destination, or at least can be bearable if there are people who recognise it and admit it to their world. The second effect is that this way of comforting ultimately offers a possibility for attachment, because it restores a social-communicative relationship, a community of meanings and people (or even it is a community with only one person). It counteracts the chaos and the loneliness that are paired with the loss of existential security. Baart (2001) states that comfort derives its power from the loving and careful invitation from the comforter, by which the loneliness of the sufferer is broken through. From his study on the presence approach, he concludes as follows: "[R]emoving or decreasing loneliness and the recognition of the loss and the connected desire: this is apparently what it is all about in the first place" (Baart, 2001, p. 695).

Contributing to identity and autonomy

Good care contributes to identity and autonomy, as discussed in paragraph 5.4.5. In every life story with a biography 'interrupted' by traumatic experiences, a serious ailment or otherwise, identity and autonomy are at stake. Individuals have to find a new relation to a specific vulnerability and its personal and social consequences. Especially when care concerns people whose life is marked by traumatic experiences, alienating psychiatric phenomena, hospitalisation, social and material losses, the impact on identity and autonomy requires special attention. Good care includes the attention for identity and autonomy. It considers how identity and autonomy are affected and it helps to reconstruct identity and restore autonomy.[48] This is done by creating within the interpersonal space the room for talking about the experiences of the person, and the way in which the person experiences him- or herself with regard to these experiences. By listening, reflecting, recognising and affirming, the person is supported in this process of (re)identification. Narrative approaches as used in recovery and life review groups can be helpful here. Finding the own identity or the self often means that rehistorisation takes place. By rehistorisation I mean that the person goes through a process of life review, which entails going over what has happened to him or her in an attempt to find explanations, thereby developing an explanatory framework, a framework in which the identity can be located (Petry, 2003). Another phenomenon is that reappropriation takes place. The person becomes the owner of the identity. The alienation caused by the mental illness and/or by social exclusion is reduced to

[48] This is also confirmed by a study by Driessens and Van Regenmortel (2006) among people living in poverty. They attribute three autonomy-raising tasks to professionals: (1) giving insight and an overview of the own life situation and providing new options; (2) teaching new or additional skills; and (3) most fundamental: helping people to believe in themselves again. The authors speak of "developing autonomy in connectedness" (Driessens & Van Regenmortel, 2006, p. 213).

a level at which the person knows how to separate the own self from experiences caused by the disease or by the hospitalisation.

Another way of supporting this process as seen in the narratives in Chapter 3 is by helping the person to connect to social environments and to engage in activities. By having real-life experiences, a sense of self can be developed. Many participants in my study used social niches for this purpose. From the narratives it is learned that the discovery or rediscovery of strengths or talents is an important form of empowerment of the identity; for example experiencing that social skills are still intact or discovering the talent to write poetry. A new sense of self is constructed by both subjective self-perception and the interaction with others, confirming (or denying) elements of the identity, such as personality traits, virtues and talents.

Autonomy is also promoted if someone can take care of the personal niche. Integrating the vulnerability or disability into the identity, which also implies a certain acceptance, seems to be a condition to have a more or less stable basis on which to lead a life that can be self-directed. Identity and autonomy are connected to both a personal symbolic world and an outside world. In finding a balance to own convictions and the mainstream discourse of identity in society, a caregiver can function as an in-between. He or she can in a way represent the world and offer him- or herself to the person as a mirror and a source of information. Wilken and Den Hollander (2005, p. 146) use the notion of "object presenting" of Winnicott (1965) to illustrate this intermediary function. They state that the professional represents the following three worlds:

- The personal living world of him- or herself, including his or her own life experiences
- The norms and values of the environment and the community in which the interaction takes place
- The reality of the 'big world', the society with its norms, rules and structures

5.5.3 The society

Until now I have discussed two perspectives of the objectives of good care. The first was the desired outcomes from the perspective of the care recipient within the relationship with the professional (paragraph 5.5.1). The second was the desired outcomes from the perspective of the professional and his practice (paragraph 5.5.2).

The final part of the ultimate aims of good care concerns the question: What are the ultimate aims of good care, seen from the perspective of society? A central notion here is social inclusion. I translate the desire of the person in a marginalised position, which is the basic desire of every human being, into a perspective to be desired by the human community as a whole.

Table 5.6: Goods realised from the perspective of society

2. Objectives	
2.3 The ultimate aims of good care, seen from the perspective of society	
Social-political	• Inclusion of others with respect for their otherness (social participation)

In the tenet of autonomy and vulnerability I discussed the issue of social participation and social inclusion (paragraph 5.4.5). Social inclusion is the opposite of social exclusion.[49] The concept of social exclusion refers to those members of society who are denied access to goods and services because of their race, gender, religion, disability, and so forth; lack adequate resources to be contributing members of society; and are not recognised as full and equal participants in society.

Social exclusion is a complex and multi-dimensional process.[50] It involves the lack or denial of resources, rights, goods and services and the inability to participate in the normal relationships and activities available to the majority of people in society, whether in economic, social, cultural or political arena.[51] It affects both the quality of life of individuals and the equity and cohesion of society as a whole (Social Exclusion Task Force, 2009).

Although the starting point for discussions about social inclusion usually is social exclusion, social inclusion has value on its own as both a process and a goal. In paragraph 5.4.5, I approached social inclusion from the perspective of the professional, whose challenge is to support the person with the task of social reintegration. In this section, I approach social participation from the perspective of the community. Here the ideal is that all members are considered of equal value in a community. Everybody has access to the valued goods and services in society, regardless of any disability.

[49] Social inclusion emerged as an important policy concept in Europe in the 1980s in response to the growing social divides that resulted from new labour market conditions and the inadequacy of existing social welfare provisions to meet the changing needs of more diverse populations (Ebersold, 1998). By 1989, the European Economic Community (EEC) began to link social exclusion with inadequate realisation of social rights. In 1990 the European Observatory on National Policies for Combating Social Exclusion was established to examine "the basic rights of citizenship to a basic standard of living and to participation in major social and economic opportunities in society" (Cousins, cited in Barata, 2000, p. 1). In 2000, European Union leaders established the Social Inclusion Process to make a decisive impact on the eradication of poverty by 2010. Since then, the European Union has provided a framework for national strategy development as well as for policy coordination between the member states on issues relating to poverty and social exclusion. Recently, in November 2009, the European Community has ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The UN CRPD binds its state parties to a revision of all existing legislation, policies and programmes to ensure that they are in compliance with its provisions. Concretely, it will mean actions in many areas such as access to education, employment, transport, infrastructures and buildings open to the public, granting the right to vote and to political participation, ensuring full legal capacity of all people with disabilities, and a shift from institutions in which people with disabilities live separated from society into community and home-based services promoting independent living. All the institutions of the European Union will now have to endorse the values of the Convention in all policies under their competence: from transport to employment and from information and communication technologies to development cooperation. It also means that they have to adjust the accessibility of their own buildings and their own employment and communications policies.

[50] Burchardt, Le Grand and Piachaud (1999, p. 227) define social exclusion as follows: 'An individual is socially excluded if (a) he or she is geographically resident in a society, (b) he or she cannot participate in the normal activities of citizens in that society, and (c) he or she would like to so participate, but is prevented from doing so by factors beyond his or her control'.

[51] In general, key factors contributing to social inclusion are considered to be adequate income; good mental and physical health; low risk of crime and low fear of crime, good quality neighbourhood; provision of appropriate care; mobility and access to transport; good social networks; good access to suitable local services; opportunities for civic participation and cultural activities; use of basic financial services; employment, learning and skills opportunities; opportunities to use digital technology; suitable, well-maintained housing; suitable information, advice, advocacy and redress; and use of common consumer goods.

While discussing the tenet of diversity, I pointed to the tendency of dominant socioeconomic discourses to exclude people who are different by ignoring or eliminating 'strangeness' or by denigrating people with disabilities to second-rank citizens. Honneth (1995) regards struggles for recognition in which the dimension of esteem is central as attempts to end social patterns of denigration in order to make possible new forms of distinctive identity. But since esteem is, in Honneth's view, accorded on the basis of an individual's contribution to a shared project, the elimination of demeaning factors does not provide esteem directly, but rather establishes the conditions that enable people to build self-esteem by contributing to the community. (In terms of denigration I would like to include here issues of stigmatisation, including self-stigmatisation, and discrimination). Honneth states that social inclusion only becomes possible if an entire community, and not just one subculture, takes esteeming each individual as a point of reference.

An ideal society also encourages participation and development of all its members. Van Regenmortel and Fret speak of an "empowering society [which] creatively uses the capacities of individuals, organisations, groups and communities, leaves space for autonomy, stimulates collaboration and offers reinforcement when necessary" (1999, p. 302).

Box 5.5 The dangers of inclusion

There are also risks associated with using the notion of social inclusion. I use the thoughts of Meininger, Stiker and Shakespeare to sensitise the reader about some dangers of the social inclusion notion. These considerations are specifically about aspects of equality and difference.

(1) Herman Meininger (2007) has studied social integration issues for people with learning disabilities. He states that thinking in the contemporary care market, in which people with learning disabilities are also considered autonomous consumers, in many cases is a 'concealment' of differences between people that should be politically relevant. He says that the danger is that it becomes "a rhetoric which is hiding the development of new forms of dependency" (Meininger, 2007, p. 30). Meininger (2007, p. 30) states as follows:

"We see those new forms of dependency develop where people with an intellectual disability are confronted with the boundaries of the desire to be just like anybody else, the boundaries of the idea to have an unlimited freedom of choice and to be able to have total direction over the own life. We see this new dependency develop in the loneliness and social redundancy were many people with an intellectual disability are suffering from […]."

(2) The French scientist Henri-Jacques Stiker did an interesting analysis of the ways in which societies have dealt over the past century with the integration of people with a disability (Stiker, 1999).[52] The core of Stiker's analysis is that in Western thinking 'being different' (and in each period of the history of Western culture this is defined in another way) appears as something that has to be assimilated or has to disappear. The more physical, mental and cognitive differences are less visible, the more a society seems to boast about its status as a dignified human society. This integration can be reached through different assimilation

[52] I gratefully use the summary and interpretation given by Meininger (2007).

strategies, but at the background there appears the ideal of a society in which differences between people are erased ('social erasure'). Stiker shows that in all times, strategies of thinking, speaking and acting can be found that have as objective to adapt people who are physically, mentally and cognitively different to the social norms that prevailed at that time.

These strategies reached, according to Stiker, their preliminary high point in the second half of the 20th century. The integration ideal is then based on a rehabilitation principle in which the idea is maintained that in the end, all differences can be erased. This happens through scientifically developed prosthetics, education and training programmes, and medical interventions. It also happens by way of cultivating the wish of disabled individuals to adapt themselves to the figuring social norms. Stiker sees in our time the appearance of a culture in which attempts are made to complete the project of identification, of equalisation of all to all. The consequence will be that people with a handicap are diluted in a large and uniform social collective. Physical exclusion will no longer be necessary. The technocratic and economic-oriented society redefines each disability as a support need which every citizen has now and then, for which nobody has to be ashamed of[53] and which can be met by way of administrative, technical and commercial solutions. However, Stiker (1999) states that behind this smooth social facade differences, contradictions and the margins of existences remain intact, and people realise this all too well. The problem of current society is not so much the lack of integration, but the forcing along scientific, technological and political lines of an integration into a socially constructed identity in which identity is formed by the fusion with the 'equal' and the 'normal'.

In Stiker's analysis, the image of a 'new incarceration' of people with a disability appears: the incarceration in the normal, the familiar, the socially accepted. According to Stiker (1999), the background of this new incarceration forms the unthinking premise of an empirical normality, a logic of the 'normal' or 'ordinary', which construes the 'extraordinary' or the 'special' as a threat or a danger.[54]

What we tend to see in our social reality as processes of exclusion, Stiker defines as integration strategies on the level of our thinking. Our culture understands strangeness and difference only by normalising it, by making it invisible, by under- or overestimating it.

If this analysis is correct, shared perspective thinking, in which a premise is put on the inclusion of (part of) the perspective of the other in (part of) the own perspective, should be aware of the mechanism described by Stiker. The differences, the peculiarity, the vulnerability, the suffering and the struggles of the other are part of a unique identity that should not be 'equalised' or 'normalised'.

[53] About the role of shame, Meininger refers to Nussbaum (2004 , p. 336): "Human beings are deeply troubled about being human – about being highly intelligent and resourceful, on the one hand, but weak and vulnerable, helpless against death, on the other. We are ashamed of this awkward condition and, in many ways we try to hide from it. In the process we develop and teach both shame at human frailty and disgust at the signs of our animality and mortality. Both disgust and primitive shame are probably in some measure inevitable parts of human development. […] Both emotions are associated with forms of social behavior in which a dominant group subordinates and stigmatizes other groups. […] They are different and not 'normal' and the comforting fiction of the 'normal' allows the dominant group to hide all the more effectively".

[54] Meininger (2007) sees parallels between the analysis of Stiker and the theoretical thinking of Bauman (1997) and Kearney (2003). Bauman and other sociologists in his tradition state that, although in postmodern society diversity seems to be idolated, this is only a disguisement of the dominance of the fundamental ideals of rationality, order and consumerism, and of new thresholds for full inclusion in the culture of modernity.

(3) Tom Shakespeare, well known for his academic work in disability studies, pleads for a more comprehensive view of disabilities (Shakespeare, 2006). When comparing the emancipation struggle of women and minorities with the emancipation struggle of people with disabilities, he sees considerable similarities but at least one important difference: the disability that cannot be removed by political action. Disability includes intrinsic limitation and disadvantage. Acknowledging this difference also means that the specific vulnerability and the related dependence on care and support of others should be acknowledged. He states that a distinction should be made between the inequality caused by the disability, which creates per definition dependence, and the equality in terms of general human needs and rights. People with a disability can perhaps economically contribute less to society because of their disability and probably require more or more specific resources to be able to function as an autonomous citizen. Simply creating equal opportunities is not enough; it may require the redistribution of resources. Disabled people are among those who need more from others and from their society (see also Driessens, 2003).

MacIntyre mentions the political implications of this reality:

"Our interest in how the needs of the disabled are adequately voiced and met is not a special interest, the interest of one particular group rather than of others, but rather the interest of the whole political society, an interest that is integral to their conception of their common good" (1999, p. 130).

Shakespeare (2006) uses the notions of Fraser (1995), who argues that (radical) social movements often combine a challenge to socioeconomic injustice with a challenge to cultural injustice. Fraser (2000, p.112) distinguishes between the "politics of redistribution" and the "politics of recognition". What she calls "bivalent collectivities" suffer both socioeconomic maldistribution and cultural misrecognition in forms "where neither of these injustices is an indirect effect of the other, but where both are primary and co-original". In these cases, remedies for the two injustices may pull in different directions. The politics of recognition may lead to a group identity, which may keep stigmatisation and social exclusion intact instead of removing it, while it may not have the effect of improving the allocation of resources.[55]

Finally a personal remark. I believe good care should include the stand to promote social inclusion. This inclusion starts within the provision of care itself: treating people as equal human beings and considering it a basic principle to work in accordance with their needs on the basis of participation and partnership. Good care will pay careful attention to processes of exclusion and human rights, both inside and outside the care system. When people with disabilities are cut off the normal social environment, for example because of a hospitalisation, good care will attend to restoring these relationships. The discourse on good care therefore has political implications. It will contribute to the transformation of a society in which there are equal opportunities for every citizen. The political dimension of good care is derived from the ethical foundation and the tenets described in this chapter. For the objective of an inclusive society, particularly the tenets of diversity, recognition, autonomy, and empowerment are relevant.

[55] The alternative Fraser proposes is not to seek recognition as a disadvantaged group, but in terms of individual status. She suggests that "to view recognition as a matter of status means examining institutionalised patterns of cultural value for their effects of the relative standing of social actors" (Fraser, 2000, p. 113).

Chapter 6 Contributions to a practice of good care

In the previous chapter an ethical foundation, six tenets, and objectives constituting a discourse of good care were described. In this chapter two more elements of a discourse of good care will be presented. First the characteristics and qualities that appear as relevant in the analysis of the narratives are explained, followed by methodical aspects of a practice of good care.

6.1 Characteristics

In this paragraph, three types of characteristics will be explicated. The first are the characteristics of both care receiver and caregiver as they appear to be relevant from the analysis. The second are the characteristics of the position of the professional. The last category concerns the personal qualities of the professional. The next table summarizes the different types of characteristics.[56]

Table 6.1: Characteristics relevant to the discourse on good care

3. Characteristics	
3.1 Relevant characteristics of care receiver and caregiver (paragraph 6.1.1)	Care receiver: *- Different (not crazy, or excluded)* *- Vulnerable yet of value* *- Has strengths (not only weaknesses), is able to contribute to personal wellbeing and the wellbeing of others* Caregiver: *- Human and competent, moral professional* *- As vulnerable as the care receiver, basically not different*
3.2 Characteristics of the professional position (paragraph 6.1.2)	*Change of perspective with preservation of position* *Role and identity that are chosen by a good professional (belonging to good care)* *The responsibilities accepted or taken by the good professional (belonging to good care)* *The nature of the relations (belonging to good care) in which the good professional engages and which he or she maintains*
3.3 Qualities of the professional (paragraph 6.1.3)	*Virtues of the good professional in the right position* *Dispositions of the good professional in the right position* *Abilities of the good professional in the right position*

[56] I use the word 'characteristic' here as a collective term for a varied range of features and capacities, which have different meanings and levels.

6.1.1 Characteristics of care receiver and caregiver

With regard to the relevance of good care, the following question must be answered: Which qualities or characteristics (of care receiver and caregiver) came to the fore from the analysis above and are (the most) relevant? I approach this question from the perspective of both the care receiver and the caregiver.

On the side of the *care receiver*, three aspects became evident from the empirical data. There is a strong appeal to regard the person as different but not crazy, non-accountable and being put off. The second appeal is to see and acknowledge the vulnerability, and the consequent sensitivity for certain stress factors, suffering and so on. This does *not* mean that the receiver is a lesser human being. The third appeal is to see and acknowledge the strengths of the person. The person wants to be regarded as a relational being, a person with a biographical and social context, someone with a strong desire to lead a meaningful and happy life, to be part of society and to enjoy the same rights as other citizens. The person strives at (increasing) personal wellbeing, but is also capable of contributing to the wellbeing of others.

What seems less relevant (note that I do not say irrelevant) is the specific nature of the problem or how others regard the person. The crux is how the professional involved regards the person and whether he or she can see the person from a multiple perspective, answering the appeal to see the other as a fellow human being, with different strong and weak sides incorporated into one person and trying to match the reality inside with the reality outside.

On the side of the *caregiver*, qualities can be summarised in two aspects. The first is that the professional is regarded as a human and competent professional, acting on the basis of moral values. Part of this humanness is a gentle, human-loving approach. The second is that the professional is basically as vulnerable as the care receiver. In essence they are not different, in terms of both being human beings that are fragile by nature (Baart, 2007; Ricoeur, 1990). Acknowledging this creates equality in this sense. Acknowledging a common human characteristic as being vulnerable and mortal may help to give counterweight to the illusion of positivist science that everything could be improved or repaired. That a professional has to be competent seems obvious. However, these competences surpass the mere technical or methodical competences. Besides the abilities needed on the level of a relationship and the level of needs (as mentioned in paragraph 3.12), competences are also related to being a sympathetic and moral human being.

From the perspective of the care recipient (paragraph 3.12 and Chapter 4), the following characteristics required of the caregiver emerged from my study. Between brackets I mention the notion to which this characteristic is related:
He or she can be trusted (integrity)
He or she connects with me (engaging)
He or she understands me (understanding)
He or she takes me seriously (recognition)
He or she affirms me (affirmation)
He or she offers safety (securing)
He or she offers support that is experienced as benefit (strengthening)

Although people in the care-receiving position want the professional to be competent, this competency is not restricted to knowledge about pathology or therapeutic measures. Professional competency encapsulates all seven areas listed above. Being able to connect requires social and communication skills, perceptiveness, responsiveness to communicational messages on different levels (affective, rational), and using a 'following' mode (mobile, flexible). Being morally virtuous requires, among other things, to be able to be trusted and to remain present and loyal.

From the narratives it appears that persons foremost want a fellow human being who is willing to be an ally, who also has vulnerable sides and makes mistakes. A good professional is not perfect. He or she is honest about the possibilities, feelings towards the client and his or her situation and is not afraid to show what bothers him or her.

6.1.2 Characteristics of the professional position

Basically, in every practice a professional has to constitute a personal and professional position. This position is co-created with the person or people to be served. The position is not merely given by the formal role of the professional as a professional who is expected to deliver certain services. A more precise position has to be developed that is mainly situated on a relational level. These conditions are created by practising the notion of care responsiveness (see paragraph 6.2.2). The professional has to join the perspective of the other in a way that causes the client to respond positively. A positive response develops when the formal and informal aspects of the position are considered as (potentially) meaningful and beneficial. The position the professional is assigned to has to be accepted by the professional him- or herself. It has to be in accordance with his or her ethical standards and competences.

Formal aspects relating to good care are divided as follows:
The change of perspective with preservation of position
The role and identity that are chosen by a good professional
The responsibilities accepted or taken by the good professional
The nature of the relations in which the good professional engages and which he or she maintains

An overview of these aspects is displayed in Table 6.2.

Table 6.2: Characteristics of the position of the professional

Characteristics of the (professional) position	
Change of perspective with preservation of position (paragraph 6.1.2.1)	• Perception of the care receiver is point of departure • Includes notion of care responsiveness
Role and identity that are chosen by a good professional (belonging to good care) (paragraph 6.1.2.2)	• Basic position should be clear • Partnership • On this basis being able to take symbolic, flexible positions
Figurative/symbolic *Societal* *Literal*	• 'Fellow man', 'as a friend', a 'watcher' • Citizen • (Normative-reflective) professional
Responsibilities accepted or taken by the good professional (belonging to good care) (paragraph 6.1.2.3)	• Formal and informal responsibilities • Commitment to serve
The nature of the relations (belonging to good care) in which the good professional engages and which he or she maintains (paragraph 6.1.2.4)	*Symmetry* • Reciprocity • Interdependence *Working with powers* • Acknowledging powers and powerlessness • Dialogical and power-free relationship *Continuity* • Being there as long as needed

6.1.2.1 Change of perspective with preservation of position

It seems important that a professional is able to remain at his position (being himself as a person and keeping the professional role) but at the same time seeks to understand the perspective of the other. The perception of the care receiver is the point of departure. The professional engages in a dialogue in order to try to understand the perception of the client. He or she exposes him- or herself to the experiential world of the other, trying to sense what this world looks like. I here refer the reader to theories on social constructivism (Berger & Luckmann, 1967). The core of this theory is that people (re)construct their reality in the interaction they have with each other. For effective collaboration it is essential that professional and client, in the contact they have, are underway to a more or less shared reality construction (Wilken, Ravelli & Van Doorn, 2009). I call this working to reach a shared perspective. Although the minute a professional and a client meet they influence each other, the stand of the professional is to leave to as great extent as is possible an open space for the other to reveal him- or herself and his or her construction of reality.

The professional starts with an open mind and a blank record. This does not mean that information about the client, for example from medical records, is not known, but this should not come in the way of the personal information given by the person. A shared perspective, or interpersonal space, is only constructed *after* the person has had the chance to unfold his or her perspective, and after the professional has reflected on this perspective, in order to determine his or her relation to it. The professional should put all the pieces of the perspective of the person together. From my research it appears that important aspects of this perspective are the cognitions the person has with regard to:

- his or her identity
- his or her disability
- autonomy
- desires regarding quality of life
- the need for care and support
- how care and support should be provided

While creating and maintaining a shared perspective, the professional constantly attunes to the perceptions of the person. This is essential in the notion of care responsiveness (paragraph 5.6.2). Throughout all the stages of the care process, the professional observes how the person responds to what is happening. From this position, the professional is able to stay tuned. It requires a constant flexibility, a 'moving with', and constant reflection and learning. Following the perspective of the other does not mean that the perspective of the professional is abandoned. On the contrary, working this way *is* the perspective of the professional, and in the interpersonal space and the shared perspective, the own personal and professional experiences of the professional are linked to the perspective of the client. However, the professional uses and maintains his professional framework, which allows him or her to connect in an optimal way to the person. This is considered to offer a solid base for the provision of good care.

6.1.2.2 Role and identity that are chosen by the professional

In the role and identity that are chosen by a professional, the professional's basic position should be clear. On this basis it becomes possible to take different figurative, flexible positions. A care recipient has to know what he or she can expect from a professional. A specific role might be explained in terms of the formal function the professional has. A distinction can be made between a position at the beginning of the relationship and what may develop in the course of the relationship.

At the beginning an intention might be pronounced to want to obtain a good understanding of the needs of the person, and a commitment to deliver services in order to meet these needs as well as possible. Rapp and Gosha suggest that a professional manifests in his or her behaviour "this new way of being together" (2006, p. 89), expressing from the start that the main purpose of the professional is to assist the person in achieving his or her goals, that the client is the director of the helping process and that the role of the professional is to help the person locate opportunities, options and resources desired, and to assure that his or her personal rights are respected.

In the course of the process the basic professional (formal) role might remain the same, in terms of the formal position, but the figurative or symbolic roles may vary according to the specific relationship and needs.

Partnership

The basic relational configuration for good care can be characterised as *partnership*. Care recipients conceive good professionals as people with whom they can form an alliance. This alliance can serve different objectives, varying from assuring safety to disease control, from developing self-confidence to attaining suitable housing. The word 'partnership' suggests that both parties are engaged in a common project, in a process of 'co-creation'. Partnership is also an expression of equality. There is no hierarchical relation in which one person stands above the other. Ridgway (2001) states that in the journey of recovery, support and partnership are necessary. Topor (2001) concludes that only if the relationship develops into a kind of partnership, will professional start to become a relevant actor in a recovery process. Wilken & Den Hollander (2005, p. 137) state that "developing a working alliance, or ideally speaking, a partnership with a client, is conditional and instrumental for services provided to the client" (p. 137). Different studies confirm that people receiving services have more appreciation for services in which partnership is emphasised (Ghesquière, 1993; Vandenbempt, 2001)

McCrory (1991) refers to the concept of *alliance* as entering into an agreement with a common goal. McCrory contends that this goes further than a therapeutic relationship: It is a growing positive transfer, a commitment that is motivating and promising. The basis of the alliance is formed by respect, trust and goodwill. He also maintains that a common goal has to be set, thus committing the care worker and the client to work together on the desired stability, recovery or development. All the parties, including the family or others closely involved with the client, should realise that this is not a simple process. Conflicts can arise repeatedly, resistance is very common, and there might also be mutual ambivalence. McCrory says that when people do not want to see this, the alliance is in danger and an effective relationship is an illusion. If the parties participate together in a process that causes pain, tension and insecurity, commitment from both sides and the courage to take risks are required. Consequently, the care worker must first ensure safety and deploy his or her expertise to clarify risks and expectations.

On the basis of this partnership concept, I discuss three types of roles and their characteristics, which seem to be important for the discourse on good care. These are the figurative/symbolic role of a friend, the societal role of a (fellow) citizen and the literal role of the professional.

The professional in the position of friendship

The first aspect of the role and identity of the professional is the professional on the position of companionship or friendship. From the narratives in Chapter 3 it became evident that values such as equality, reciprocity and intimacy are considered as goods[57]. These can be summarised in the notion of companionship or friendship.[58]

[57] A good is something which is experienced as beneficial. I am following the definition of MacIntyre (1985, p. 285) who is speaking about 'internal goods', the goods which are immanent to the practices in which

Box 6.1 Notions on the position of friendship

Vosman (2005, p. 62) has developed further notions on "friendship as a model for professional care". He starts from the assumption that in friendship, the good is central. Characteristic for a friendship is that it is a reciprocal relationship. Vosman uses the word 'liveliness' to indicate that friends keep each other 'vital' or 'alive' by giving each other company, attention and joy in sharing thoughts and activities. Friends act towards each other and establish a long-term attitude; thereby, friendship is a virtue. Although two people can be quite different, according to Aristotle, equality can be reached if the expressed affection for each other is accorded with the merit or position of the other. Giving *and* receiving are equally important in a friendship.

When positioning a caregiver in relation to friendship, Vosman follows the conceptions of Ricoeur (1992) and Biggar (1997). Ricoeur situates friendship in modern society in the intersection of the public and private spheres. The idea of the 'good' in friendship should also be the basic idea for political policy making. Biggar suggests that friendship is basic to all forms of community. Biggar argues that a society is not a convenient arrangement in a predetermined democratic order, but is formed by 'friendly connections' between citizens. Friendly 'virtues', such as honesty and confidence, are indispensable for creating relationships. In an orderly community, citizens participate in different forms of friendship, which are necessary as a basis for community life. According to Vosman, the professional will stand "on the position of friendship" (2005, p. 69).

Within this context, a relation between a professional caregiver and a care recipient can also be positioned in the intersection of the public and the private. Broadly spoken, a professional is a 'public servant', representing a society that provides services to its needy citizens, and has ideas about what professional care should entail. In addition, the professional also represents an agency that executes the designated services. A professional is also a private person. The contact and relationship between professional and client does not exist in the private sphere (of the professional), but primarily in the public sphere. There is a major inequality here, since in the relationship from the perspective of the client, it exists in the private sphere, while from the perspective of the professional, it exists in the public sphere. Friendship, in the way it is conceived here, can form a bridge between the two (see also paragraph 5.5.3). The notion of Biggar applies here, who states that "friendship is a relation in which someone is engaging himself personally" (cited by Vosman, 2005, p. 69).

Vosman elaborates on this notion using the work of the phenomenologist Sokolowski (1985; 1992). Sokolowski's reasoning follows a couple of steps. The first step is: I wish you something that I see as good for you and, moreover, consider it as a good for you. Then, a second step is: As such, as good for you, and insofar it is a good for you, *I* want it too, and I

individuals are engaged. In paragraph 5.7 I will make a distinction between those goods realised *in the* practice, and goods realised *as a result* of this practice. See also footnote 2 and paragraph 5.7.1.

[58] The professional does not primarily 'feel' trust or confidence, but builds this up in the practice. He or she uses a number of virtues and translates those into corresponding behaviour. Standing on the moral position of friendship does not mean per definition that companionship will develop. This depends on the client and whether he or she perceives this as a good. There is nothing wrong if companionship does not develop. Here too, the notion of care responsiveness is important. A position of friendship does not mean that everything is shared. What seems to be appropriate is told. A feeling of intimacy is not the objective. Appropriateness is related to the objective of revealing which good is at stake.

see it as a good for me. I see it as a good for you that you can find rest, or that you receive care now that you're very ill. *That* I see this as a good and want this for you, I take as a good for myself. Your good can cost me a great deal of effort, but it matters to me that you get care; I don't want to live in a world in which is not given to you what you need to live and to be happy. This is exactly the position of friendship.

Baart (2005) concludes that there is no evidence that companionship and professionality are contradictory.[59] On the contrary, there are good reasons for making friendship part of the professional discourse. However, the connection makes a great appeal to take good care of the relationship. It requires a great deal of reflexivity to avoid on the one hand that companionship becomes something artificial and hollow, and on the other hand that physical and moral boundaries are crossed.

For professional care it is not necessary to develop all kinds of personal preferential friendships. But it is possible to take in all relationships the position of friendship, and to develop a practice from this position. Taking this position makes it possible to discover what is good in one's acting towards another person. The professional is temporarily in this position, as long as the relationship goes on.

Vosman (2005) mentions four presumptions for taking this position. In the first place, the professional should not regard him- or herself primarily as a 'technician', but as a citizen who possesses professional knowledge and who applies this in a profession and in a relationship that is not purely public and not purely private. This implicates a political vision of professionality. Secondly, this position implicates that the equality between caregiver and care receiver is the embedding in which the inequality in position and knowledge is included. A third presumption is that the professional be prepared to be and stay active, in a continuing practice of self-questioning in the line of Sokolowski's reasoning (see box 5). Vosman states the following: "Developing a practice in order to stand on the position of friendship does not settle for filtering away what is morally at stake. On this position, one is actually looking for it. One is taking uncertainty for granted and examines what morally spoken is relevant" (2005, p. 71). This requires active control. The last presumption is that a relationship between a professional and a care receiver is not reciprocal in the sense that the recipient does not necessarily also wish 'the good' for the professional. Yet, acting as a fellow-citizen he can do so (Biggar, 1997).

In addition to the above I would like to add that a professional 'as a companion' can also fulfil the role of a 'watcher'. In a number of narratives in Chapter 3, it becomes clear that people assign this role to the professional. By speaking about 'watching', they mean that the professional keeps an eye on them and assures that it is going well with them, but also to become active if they observe that things are not going so well. Having the need for a 'watcher' is a result of the vulnerability and with the need for safety. Ascribing

[59] The role of friend can partly also be substituted by the metaphoric positions of a brother, a sister, an aunt, uncle, father or mother (Baart, 2005), although family-like positions have a different character than friendship-like positions.

'watchmenship' to a professional is associated with trust and confidence. The professional who accepts this role is responsible for the successful accomplishment of this role.

In conclusion, the metaphoric position of friendship expresses the value clients attribute to a professional who is near to them, who is personally engaged and is willing to engage in a reciprocal relationship. The position expresses the intention of wishing a good life for the other.

The professional as citizen

The second aspect of the role and identity of the professional is the professional as *citizen*. In Chapter 3, the notion of citizenship was developed from the perspective of the care receiver, which was associated with (the desire) to belong to the world and to fulfil valued social roles. In Chapter 4, I added to this notion the entitlement to human and civil rights, rights that are often denied people in marginalised positions. By translating these conceptions to the perspective of the professional and adding insights from the tenets described in this chapter so far, I now briefly discuss five aspects of this role.

(1) Citizenship is a foundation for friendship

In the paragraph above it is explained that a professional in the position of friendship can take this position because he or she is not 'just' a professional but also a (fellow) citizen. Professional care is sketched in a domain that lies across the spheres of the personal and the public. For the professional, the interpersonal space that is created in concurrence with the client crosses both his or her own personal space and the public space in which he or she is employed. Within this limited intersection, he or she searches for and establishes friendship. This personal-professional form of friendship is always embedded in the conception of citizenship.

(2) Citizenship promotes equality

There are other reasons for using citizenship as a framework. One is that by doing so, on a level of citizenship, both actors are equal. On a human level they share the same basic vulnerability and dependency. On a political level they share the same rights and duties as other citizens within a given society. This does not mean that there is no inequality in the way citizenship is or can be 'practised'; on the contrary, these differences may be quite large (see also *symmetry* in paragraph 5.5.2.4). By articulating these differences, the professional may, given his or her available resources, help the person to achieve 'full' citizenship.

(3) Citizenship enlarges the professional domain

The notion of professional as citizen enlarges the scope of the professional. When working with an individual, the social context of the person is always taken into account. The professional does not operate outside a social system or in a separate social system, but is part of the 'larger world' and also represents this world for the care receiver. This includes a representation of the reality that counts for every person in a given society.

(4) Citizenship brings matters of injustice into sight

A fourth aspect, a political one, is that citizenship brings matters of injustice into sight. It may place the professional in the position of advocate. Where (citizen's) rights are at stake, a professional could play a role to help to solve such problems.

(5) Citizenship involves bridge building

A fifth aspect is that citizenship places the professional in the position of 'bridge' or 'bridge builder' between the client and the community. The professional scope is not only an individual client, but also his or her position in the community. This community might be his or her personal social network, but also the neighbourhood in which he or she lives and his or her position in the labour community and the social welfare system. If the goods of a person are related to, or can be found in, the community, good care (also) has to involve actions towards the community. I connect the role of the professional as a citizen here to the objective of *social inclusion* (see paragraph 5.7.3). Professionals and the agencies they are working for should incorporate contributions to social participation in their work.[60]

Box 6.2 The professional in the community

Van Ewijk (2008) strongly advocates a contextual community approach. He refers to social professionals as

> '... builders, as bridging professionals or even as (social) architects, creating a social fabric to hold communities and societies together. In this contextual approach we are de-categorizing, de-labelling and deconstructing because in the micro context people are more individualized and personal. Social professionals in contexts are usually not starting from a category, or a target group, but from a context felt as problematic and to intervene for improvement or to do everything to sustain a certain supportive context.' (2008, p. 12)

A contextual community approach can also be placed in the context of a changing society in which active, participatory citizenship is sought to be revitalised. Citizen-based perspectives are nowadays promoted throughout the European Union. This citizen- and community-orientation aims at activation, social responsibility and self-determination related to social rights and related obligations. Here the social professional has a mission, a social assignment to implement a concept of citizenship (Dente, 2007). Van Ewijk (2009a/b) and Van Ewijk, Wilken, Verhagen & Menger (2009) have introduced in terms of this new professional orientation the notion of *citizenship-based social work*. Van Ewijk (2009c, p. 69) defines this as a field of action, knowledge and research that "aims at integration of all citizens, and supports and encourages self-responsibility, social responsibility and the implementation of social rights". A citizenship-based approach implies that social professionals aim at strengthening and supporting individuals and their informal networks. They never replace these networks, but are additional to them whenever necessary.[61]

[60] This can be done on an individual level, but also on a collective level, for example by making connections between a facility situated in a neighbourhood and people living in this community. Facilities such as nursing homes or day centres can be opened up to the surrounding community instead of being segregated from it. An example is: allowing people from the neighbourhood to use the restaurant of the nursing home. Also, the reverse is possible, for example making community centres, schools and sports facilities more accessible to people with a disability (see also Oudenampsen, 2004). Verhagen (2009) states that social interventions are often more effective in promoting citizen participation than behavioural interventions.

[61] Wilken and Den Hollander (2005) argue in favour of a comprehensive approach in which the professional is both working at an individual level, offering care and support, *and* at a community level, working in and with communities in order to raise the level of mutual support and care. In the support model as described by me

Putnam's (2000) notions of bridging and bonding from his theory on social capital can be useful here.[62] According to Putnam, two powers are necessary to create social participation and cohesion in a local community: bonding and bridging. *Bonding* represents the reinforcement of mutual ties among citizens, where norms of reciprocity and trust are important. This usually takes place among citizens who share a common identity, for example through historical roots, religion or culture. These local communities are relatively small *communities-in-the-community*, and are characterised by informal solidarity. Examples are neighbourhood associations, sport clubs, church communities, political parties and consumer groups. *Bridging* is the external focused force that can be found in networks that connect people to external resources (information streams, labour market, educational opportunities, governments and so on). Via bridging, a connection is created between different groups and organisations in society. This creates conditions for social participation. According to Putnam, this concerns 'weak ties', where no specific reciprocity and trust are needed. This network is synonymous with modern society. The network is necessary as nourishment and carrier for the local communities. Via this network, citizens are connected to each other. The network society as a whole can, however, only exist if citizens are aware of their mutual interdependence and their common interests that must be served by society as a whole. An example is safety. Safety comes about on the one hand by *bonding*, within the own small community, but on the other hand by *bridging*. The resources of the larger community are needed, for example the police and the juridical system. The same goes for health and social care.

Professionals can perform both bonding and bridging activities in order to help people in a socially marginalised position to connect to the community and to become part of *social capital* (Wilken, 2005a; Oudenampsen, 2004). Bonding activities are aimed at connecting the individual to social networks in the community. Bridging provides access to resources needed for both individual wellbeing and becoming part of communities.[63]

(Wilken, 2005; 2007b), a close collaboration is promoted between professionals who work mainly individually with specific groups (e.g. people with psychiatric of intellectual disabilities) and professionals who are engaged in community work (e.g. in community centres, schools and housing corporations). Research shows that this collaboration on the level of a determined geographical area such as a neighbourhood of a town can improve chances for participation and social inclusion, thereby contributing to the wellbeing of people in vulnerable social positions (Wilken and Dankers, 2010). The role of 'intermediary professionals' is important for facilitating processes of connecting people on a community or social network level. By increasing the strengths of social networks, people with a chronic disease or a disability do not only receive more informal support, but also have more opportunities to make a contribution to others (Brettschneider & Wilken, 2007).

[62] According to Putnam (2000, p. 19), social capital "refers to the connections among individuals - social networks and the norms of reciprocity and trustworthiness that arise from them".

[63] In the activities of the professional, the issues that I have discussed in paragraph 5.4.3 have to be taken into account. The differences of people with a disability should be respected, and not be subject to social strategies of equalisation (Stiker, 1999). This might mean that they partly realise bonding within a particular community of people with whom they share common interests on the basis of their disability experiences. People with disabilities may need special bridging efforts in order to obtain the resources they need (Shakespeare, 2006).

A normative-reflective professional

Returning to the core identity of the professional, it can be concluded that the notions discussed in the logic of good care require a specific type of professionalism. Good care, as it is described in this book, has a normative foundation, since it is based on a number of moral principles belonging to the ethical foundation which I described and on the values belonging to the tenets as discussed (presence, shared perspective, diversity, recognition, autonomy and vulnerability, and empowerment). This requires a specific sensitivity to all the elements of these tenets. Although sensitivity can also be (only) present at an intuitional level ('providing care from the heart'), I think that professionalism also requires being aware of what is experienced on a level of rational awareness. This requires reflection and the availability and constant development of a body of knowledge.[64] I consider a body of knowledge as consisting of values, skills and both professional and personal experiential knowledge. All this knowledge is 'embodied' in the person of the professional.[65] Values are often hidden in the actions of the professional or, as Pols (2004) puts it: Professionals 'enact' values. Values obtain a concrete form in daily activities.

Part of this awareness entails reflecting on the own values involved in the practice. These values also have to be confronted with values rising from the person and the context. Kunneman (1996) describes this as 'a reflective attitude with respect to content of questions and dilemmas which are coming forward'. This takes place via making conscious and argued accounted connections between (a) the quality of the own existence; (b) the content of the work; and (c) the larger cultural and social context, considered in the context of the quality of the own professional actions as experienced by clients. Professionals in social professions participate in caring for 'the good life' of their clients (Nussbaum, 1993; Ricoeur, 1990). Therefore, they constantly find themselves in a tension field between the personal life world of the client and the world of systems, justice, solidarity and private interests. Being able to make moral judgements is an important aspect of modern professionality (Driessens & Geldof, 2008; Van Doorn, 2008).

For Kunneman, normative professionalism is closely connected to the notion of equality. The professional is not superior to the client. Kunneman (1996, p. 300) states the following in this regard:

> Ultimately professionals and clients are involved in a related project, namely leading a meaningful life in which they can experience their personal value because they can be of actual meaning for others. Searching reflectively for notions about meaningful life and personal value, together with others, over and over again, forms the core of normative professionality in social professions. Normative professionality is not only determined by the way professionals are shaping the interference between their work and their existence, but also in the way they relate to the cultural and societal context in which the questions of clients appear.

A central question in the discourse on good care is: Is what I am doing as a person and a professional beneficial to the person I am serving? In order to answer this question conceptions of 'beneficiality' should be reflected upon. These conceptions are formed by

[64] See the notions of Schön (1983) and Schön and Rein (1994) about different forms of reflection.
[65] See the notions of Polanyi (1958; 1967) about tacit knowledge.

norms and values of professional and client, but also from the community and the society. Norms and values can be consistent, but can also be conflictive. Because in every situation there is a new constellation, it requires constantly finding a relation between the own beliefs, the beliefs of the client and his or her environment, the beliefs of the community (including the service agency and the professional group) and the beliefs of society. Jacobs (2010) states that this requires a continuous dialogue about values between different stakeholders involved in a particular practice. Professionals have to support clients to make good choices, which do not only serve an individual interest but also the collective interest of the community.

The normative values of the discourse on good care form a beacon, but will at the same time be constantly contested, because of this ever-changing dynamic. Therefore, normative professionalism is not a static situation but a continuous learning process. Jacobs, Meij, Tenwolde and Zomer (2008, p. 12) describe normative professionalisation as "the realisation of the power field of different norms (societal, organisational, professional and personal) in which the professional finds himself and the search for the right basis for justifying the professional acting, which can vary per situation and requires deliberation (before, during and after)". Van Houten (2008, p. 34) states that normative professionalisation implies that "equality and diversity, attention, responsibility and competence are central fixed points", thereby adding a moral content to the notion of normative professionalisation, which is consistent with the theories developed in this chapter. Central to this are the moral charge of the professional actions and the reflection on these actions. This morality is defined by an open character and a high dialogical content. The morality is aimed at the promotion of quality of life, which requires a good understanding of the judgement of the client about his or her quality of life.

In the process of normative professionalisation, in terms of the tenet of shared perspective, there is an intrinsic tension between "rooting" and "shifting" (Jacobs, 2008, p. 46), i.e. the interchange of inner and outer perspective (Van der Laan, 2006). Rooting refers to being rooted in the own culture and the life and working styles, rituals, values and language belonging to that culture. Shifting means opening up for and entering into other cultures. In the discourse on good care, the bottom-up approach (also referred to as a 'life world perspective') is favoured, which starts from the perspective of the client. At the same time, the professional should not disappear in the perspective of the client. In order words: He or she has to remain rooted in his or her own culture, although this culture is in constant open interaction with the culture of clients (tenet of diversity).

Box 6.3 A deliberative discourse

Part of this interaction is the deliberation that occurs in cases when the norms of the client (and the behaviour connected to these norms) are considered by the professional as destructive or antisocial. Jacobs (2008) pleads for a good balance between rooting and shifting. The same is true for the balance between the own culture and the culture of the system world, the world of organisations and bureaucracy. Jacobs refers to Goldner (1997), who does not speak of dialogue, but of *deliberative discourse*, as language, meaning and learning (knowledge) are interwoven with power. This means that the dialogue has productive moments as well as (sometimes simultaneously) destructive ones. This requires from the professional a specific responsiveness, an ability to sense, experience and react to the other on the basis of the reactions perceived in the own body and mind.

The professional does have to give room to the judgement of the other person, and compare this with the own judgement, so that connecting factors and differences can be explored. This requires a "double position" and a related "double reflexivity" (Jacobs, 2008, p. 47). Working as a dialogical normative professional means that in the relationship with others the own value orientation and professional identity is under critical consideration. This can be challenging as well as painful, because in the dialogue not only recognition can be experienced, but also denial and rejection. Jacobs (2008, p. 49) states that this requires courage, because

'this asks for recognition of the own vulnerability, openness towards what is experienced on a physical, emotional and rational level, about feelings, dreams and desires. It means taking risks, admitting the unpredictable and unexpected […]. Normative professionalisation is besieged in daring to pose the question: Am I going to face it, or am I going to avoid it?'

6.1.2.3 Responsibilities taken by the good professional

In terms of the characteristics of the (professional) position, I now consider the responsibilities accepted or taken by the good professional. A distinction can be made between formal and informal responsibilities. Formal responsibilities are all the responsibilities that are externally assigned to the professional role and tasks. These include the responsibility to deliver care in a competent and accountable way, use professional standards and address the needs of the recipient. The professional responsibility is "to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended" (MacIntyre, 1985, p. 187).

In Tronto's theory, responsibility is the moral component of organising care to relieve needs. I extend this responsibility to all the elements belonging to care responsiveness (see paragraph 5.6.2).

On the basis of the logic of good care, as explained in this chapter, the following responsibilities come forward:

- The responsibility to create a shared perspective understanding.
- The responsibility to create a relationship that is characterised by presence, and its constituting elements such as connecting to the life world of the other and an attentive involvement with desires. This responsibility also includes staying with the other, and not abandoning him or her.
- The responsibility to create a dialogue in which the perspective, needs and desires of the other can be revealed.
- The responsibility to include aspects belonging to diversity and acknowledge differences caused by the biography, the illness or the disability. The professional has the responsibility to keep inequality and equivalence together.
- The responsibility to include needs connected to preserving or restoring identity and autonomy in the care process.
- The responsibility to preserve the human dignity of the other. This preservation is also expressed in the attitude and actions of the professional. The moral responsibility of the professional is to conserve the vulnerable and valuable humanity and those caring for him or her.
- The responsibility to preserve and to increase the strengths of the other.

From the responsibilities listed above also emerge responsibilities that strictly speaking do not belong to the formal responsibilities of a professional, but that nevertheless belong to the professional position in good care. For example, there might be situations in which there is no use to undertake action, for example in case of a terminal disease. Nothing else can be done but just being and staying with the other, sharing his or her situation. Another example comes from a study by Karbouniaris (2009), who mentions a mental health worker who took the initiative to take care of the cat of a woman who was temporarily hospitalised.

Good care implies that professionals do not always stick to the formal boundaries of their task description or the time boundaries of their shift, but that they go beyond these if they sense that this will contribute to the relationship with and the wellbeing of the person. Formal and informal responsibilities are a combined expression of the commitment to serve and to provide the best forms of support.

6.1.2.4 The nature of the relations

Up to this point I have discussed three characteristics of the professional position: the change of perspective, role and identity, and responsibilities. To conclude this section, I discuss the nature of the relations in which the good professional engages. From the narrative analysis, three aspects came to the fore. The first is that the relationship is experienced as *symmetrical*. The second is that there is *reciprocity* and the third that the relationship is characterised by *interdependency*.

Symmetry

The professional finds him- or herself per definition in an asymmetrical position. Consistent with the angle of diversity, there are differences in role and knowledge, besides other differences caused by cultural or ethnical background, gender and age. This asymmetry should be acknowledged, but on the basis of an underlying equality. This is also the only way in which the position of companionship or friendship can be taken, since this is based on equality (Vosman, 2005). My basic statement is that by acknowledging asymmetry,

symmetry can be realised, because through the position the professional is enabled to use his qualities and resources to the benefit of the other.

From the narratives it can be learned that professionals who are experienced as really supportive of recovery and development look for ways to be additional or *complementary* to the person. They add what is lacking or missing (and thereby needed) and do not take over what a person is able to do him- or herself. This requires careful assessment of the possibilities and limitations of both person and environment.

Reciprocity

The relationship in the discourse on good care is characterised by *reciprocity* or mutuality. This means that there is constant interaction and communication between the professional and the person. Reciprocity is expressed in the notions of a personalised relationship, expressed by sympathy, constructive dialogue, collaborationship and companionship. Mutual exchange is a setting in which one affects the other and is affected by the other; one extends oneself to the other and is also receptive to the impact of the other (Jordan, 1991). Reciprocity is marked by giving and taking, by mutual acknowledgement of each other's personality, role, knowledge and experience. It refers to a situation of mutual trust and confidence. Equality is related to the notion of reciprocity. There is no one-way traffic, but an exchange. This exchange can be concretised in terms of exchanging ideas or experiences or in the act of giving and taking when it comes to activities undertaken to reach a specific goal.

In reciprocity a balance is constantly sought between giving and taking, between closure and disclosure, between approaching and distancing. Although there is a desire for connectedness, at the same time there is the fear for vulnerability. Miller and Stiver (1997, p. 81) call this "the paradox of connection". This paradox refers to a longing for affirming relationships, while the fear of connection keeps one from revealing one's most vulnerable parts, thereby preventing true connection. This paradox is in a way present for both professional and client (see also Baart, 2001). In the development of reciprocity, this paradox should be included and can be articulated whenever this helps to express feelings of uneasiness. Since the position of the professional is different from the position of the client, this asymmetry influences the way in which reciprocity is concretised. The development of the client has priority. The professional has to take care of an 'embedded mutuality'. The reciprocity is embedded in a framework that is aimed at providing the client with the space needed for recovery and development. The professional (only) shares personal feelings, thoughts and experiences if this is in the interest of the client and the relationship (Miller & Stiver, 1997).

On the one hand, reciprocity develops spontaneously. On the other hand, it is the task of the professional to create adequate forms of mutuality. This requires creating affective connectedness and at the same time evaluating the quality of the relationship seen in the perspective of beneficiality to the client. Jordan (1991, p. 80) refers to this as "separateness within connection". This responsibility is also important with regard to creating and maintaining safe boundaries. The notion of the personal niche requires that the person can maintain strict boundaries that should be respected and that others should not transgress these boundaries. The notion of the interpersonal space implies having permeable boundaries that allow interaction.

Interdependence

Reciprocity also implies *interdependence*. This notion was briefly discussed in the tenet of autonomy and vulnerability (paragraph 5.4.5). Both parties are dependent on each other, not only by fact, but also by *intention*. In the context of reciprocity and interdependence, a basic acknowledgement is that all human beings are vulnerable. Dependence and vulnerability are part of our lives. De Swaan (1990, p. 21) has exalted the practical necessity of mutuality to an issue of existential purpose and value: "That is what conveys to people their significance for their fellow human beings and that is where they find the fulfilment of their existence".

Manneke (cited in Van Heijst, 2005, p. 41) states that "dependence and vulnerability can lead to feelings of connectedness and to meaningful contacts between individuals" and that "care ethic is based on the recognition that everybody is vulnerable". Van Heijst (2005) emphasises that although this similarity is true, in the relationship between someone who is in need of care and a professional caregiver, the latter should be in a non-vulnerable position in order to be able to be of service. In a care relation, someone who is in need of care becomes per definition dependent on the abilities of others. One aspect of care-fulness is that professionals are aware of the fragility that is brought about by both the situation and the vulnerability. When the participants in my study indicated that they appreciate a professional treating them with respect, they also meant that they were glad that their fragility and their dependent position were respected. One of the worst things that could happen is that someone is hurt in his or her fragility.

Shakespeare (2006) also emphasises the recognition of the vulnerability or disability, *and* the consequent dependency on care and support. He states that in this respect, there is without doubt inequality and dependency, and not interdependency. This should be taken into account. Shakespeare maintains as follows: "A person who needs help, but cannot help others to the same extent, enters a relationship of dependency. She cannot return the favour, and consequently becomes indebted and inevitably loses some status in the interaction" (2006, p. 147). Although this is true, in my view in the course of the relationship the other should be allowed to correct this imbalance.

The position of a professional is per definition characterised by ambivalence. This is certainly true in situations in which there is an urge to protect people who are not able to express what they need, but are in a situation that they experience as seriously threatening. Conflict and aggression are sometimes present in caring. But also if verbal communication is possible, the ambivalence is present. A way of handling this ambivalence might be to use an ethic of justice as a frame of reference. This ethic provides the principle for people to receive professional care as a right and not to be dependent on a charitable form of care or kindness. It also provides the framework for free choice of service providers.

On the basis of the ethical principles as described in paragraph 5.3, the professional looks, in each individual situation, for the 'good' of the other. This requires a twofold assessment. The first assessment concerns what impedes the person in experiencing the desired quality of life and exploring the goods to be established *by* the relationship. The second assessment concerns the goods to be established *in* the relationship. The assessment of the desired

quality of life will be related to specific vulnerability factors, both individual and environmental.

In the relationship, a balance should be found between what binds and what separates (diversity). By articulating what both parties have in common (on the basis of the same basic dependency and on the basis of shared interests) and in which respect the person depends on the professional, symmetry can be found. This is the basis for 'complementary care', care that supplements what a person or his or her (natural) environment is not able to provide.

6.1.3 Qualities of the professional

In this discourse on good care I now consider in detail the virtues, dispositions and abilities belonging to the position of a professional in the discourse of good care. Although there is a close connection between the three, I make this distinction in order to distinguish the possession of basic qualities that are essential for developing a competent practice from qualities that are connected to personhood and basic attitudinal values. In the next table an overview is given.

Table 6.3: Personal qualities of the professional

Personal qualities of the professional	
Virtues (paragraph 6.1.3.1)	• Commitment and dedication; loyalty • Benevolence • Attentiveness
Dispositions (paragraph 6.1.3.2)	• Open-mindedness and open-heartedness • Authenticity • Positivity • Being disturbable, interruptible and approachable
Abilities (paragraph 6.1.3.3)	• Empathic sensitivity • Responsiveness

6.1.3.1 Virtues

The notion of virtue is generally connected to moral and ethical principles of uprightness, goodness and righteousness. It is also related to a good or admirable quality or characteristic. Three types of virtues are emphasised in the narrative analysis, namely commitment and dedication, benevolence and attentiveness.[66]

Commitment and dedication

In Chapter 4 I clustered a number of themes appearing in the narratives under 'commitment and dedication'. Participants expressed what they value in professionals in phrases such as being involved with me; being committed to my case; doing something especially for me; making efforts on my behalf; remaining faithful and loyal; being reliable; and dragging me through tough situations. These are expressions concerning professionals who are apparently deeply engaged and try what is in their power to help the person. Personal efforts are experienced in many stories as a beneficial gift.

When I translate this to a professional's disposition, this can be described as a commitment to become engaged in a relationship and a dedication to help and support the other to the best of abilities. Commitment is related to taking responsibility for a caring relationship. This is not a compulsory commitment on the basis of the professional role, but a commitment consciously taken upon oneself. The commitment is personalised: It is a commitment from *this* professional to *this* client. Dedicated professionals are willing to give themselves fully, within the limits of what is possible. They persistently persevere to find the good in and for the other. The professional does not only become committed but also stays committed as long as needed. Commitment is connected here to loyalty, duration and continuity. Dedication expresses a specific, intense effort. It symbolises an earnest attachment to the person and his or her cause. Commitment and dedication can also be related to the values belonging to the ethic of care and the other tenets presented in this chapter. The good professional strongly believes in these values and principles and is dedicated to put these in practice.

Providing care to people with long-term needs requires patience and perseverance. It requires adapting the own pace to the pace of the other. Sometimes this will inevitably lead to tension between the own mode of speed or the pace required by the organisation and the pace experienced as comfortable by the person. Besides the competency of attuning to the pace and rhythm of the other, it also requires the virtue of staying committed *even though* it requires considerable adjustments, both personal and organisational.

Benevolence

Another virtue inherent to the discourse on good care is *benevolence*. Benevolence can be described as 'wishing to do good'. It stems from the Latin word *benevolentia,* constituted by *bene* meaning 'well' and *volantem* meaning 'to wish' and 'willing to'. Benevolence is the desire to do well to others, but is also expressed as an act of kindness. It can also be related

[66] Virtue ethics emphasizes the character of the moral agent, rather than rules or consequences, as the key element of ethical thinking. I am aware of the discussion among scholars about professional virtues and "reflective equilibrium" (e.g. Van Thiel, 2009) but limit myself in this paragraph to what I can remark on the basis of my research material.

to generosity. The professional is not frugal with his or her kindness or efforts. He does not have a suspicious or negative attitude.

Van Leeuwen (2003, p. 86) speaks of a "hermeneutic openness". This basically implies openness to the whole being and not only to the deviant part. It implies a curiosity for other sides than the ones that are seen at first sight. It does not mean that one has to bear everything or that one has to glorify people, but it involves a basic respect for the other as a human being, including or even despite the way in which he or she presents him- or herself.

Attentiveness

Attentiveness can be described as the will to relate to the other, exposing oneself to the life world, conceptions, messages and appeals of the other. It is an open yet concentrated state of mind.[67] The professional puts his or her attention at the disposal of the client, but at the same time he or she has to be attentive in order to create the relationship necessary for good care. Being attentive also means that the professional has the wish to establish contact with the other and his or her world, to be invited in by the other and to let the other in.

Attentiveness comes in many different forms. Attention alone is not enough. The attention should be *attentive*, which requires a certain degree of *concentration*. The concentration is aimed at the person and what he or she expresses. To be really there for the person requires focus and energy. One cannot be distracted. It is a dedicated way of giving attention, characterised by an active listening attitude and an indication of interest. Attentiveness should be genuine.

Receiving 'personal attention' expresses that the caregiver is there for the client, as an individual. It is an exclusive event. It entails undivided attention, not having to be shared with others. From the narratives it became clear that this is often regarded as a gift. Attentiveness is also connected to time. To give someone one's time means in fact that one is giving your attention to him or her.

The value underlying attentiveness is: the will to have *unconditional attention* for the other. This Rogerian term refers to having an open mind and to not starting the relationship with a bias. Beforehand, the other does not have to fulfil any conditions in order to get the attention of the professional. Attention does not have to be 'deserved'. This is the notion of 'unconditional positive regard' as developed by Rogers (1951; 1957). Rogers states that only if a professional warmly accepts each aspect of the client's experience as being a part of that client, can the client experience unconditional positive regard. Rogers (1957, p, 101) describes this situation as follows:

[67] There is a parallel between the notion of attentiveness and the notion of 'mindfulness'. Psychological mindfulness is broadly conceptualised as "a kind of non-elaborative, nonjudgmental, present-centered awareness in which each thought, feeling, or sensation that arises in the attentional field is acknowledged and accepted as it is" (Bishop *et al.*, 2004:232). Bishop *et al.* (2004) propose a two-component operational definition of mindfulness. The first component involves the self-regulation of attention so that it is maintained on immediate experience, thereby allowing increased recognition of mental events in the present moment. The second component involves adopting a particular orientation towards one's experiences in the present moment, an orientation that is characterised by curiosity, openness and acceptance.

> It involves as much feeling of acceptance for the client's expression of negative, 'bad', painful, fearful, defensive, abnormal feelings as for his expression of 'good', positive, mature, confident, social feelings, as much acceptance of ways in which he is inconsistent as of ways in which he is consistent

The value in attentiveness lies in expressing that the other is *worth* being attended to. In the attention the value of the other is concealed (and thereby recognition is given to this value). Attentiveness contains the three forms of recognition as formulated by Honneth: love, respect and solidarity. The value of attentiveness is its intention to find the *goods* in and for the other. Being attentive means seeking what can be a good for the recipient (in this situation), leading to the understanding that is the ultimate goal of being attentive.

Attentiveness can also have a vigilance mode. In a number of the narratives of this study, participants indicated that they appreciate it if professionals watch over them and remain alert for potential risks or harm. This mode belongs to the notion of securing (see paragraph 4.5).

Attentiveness is a disposition that has to be mounted and refreshed in every contact with a client. It requires having energy and directing it towards the other. The more this sensitiveness is being practiced, the better it will be developed. Attentiveness as a virtuous disposition also requires maintenance. Aside from the physical fitness that is required for being attentive, it also requires a 'moral fitness'. The sensibility for moral experiences should be taken care of and maintained, as is the case with the virtues of commitment and dedication, and benevolence.

Box 6.4 Functions of attentiveness

Baart (2004a, p. 84, my translation) summarises the functions of attentiveness as follows:

Mainly instrumental meanings of attentiveness	
diagnosis	coming to an understanding of what is at stake
bonum	finding what can count for this person as a good in this situation
carefulness	carefully attuning to the other and making space for response
inscribeability	answering the question: Who can I be for you?
responsive	as an attentive concerned person the professional is real and does not fake compassion
Mainly content-immanent meanings of attentiveness	
social inclusion	mattering and being placed in relationship
calling to life	coming to an own existence and a personal articulation of desires
recognition	taking a valid position with respect for the difference
seeing potential	seeing more than only what is damaged
comforting	salvaging the lonely who is suffering
closeness and election	inclusion of the other who could have been overlooked

Being attentive has an intrinsic connection to being careful, here in the sense of being cautious. It is connected to the classic virtues of *prudentia* and *discretio*. The professional does not want to damage the person by being too intrusive. Within the relationship a suitable form of attention is sought.
Baart (2004, p. 50) states the following in relation to the virtue of prudence:

> [T]he prudence of attention is intermediary to let me attune my acting to the other in front of me and puts me in a nonviolent position. Attention teaches me which professional rules to choose, which to put aside and which to ignore. It […] brings me to focus on the particular, the concrete and the special […]

Being attentive and giving attention are personalised acts. It is not just the particular person who is the focus of attention, but it also the particular professional from where the attention comes from. In terms of attentiveness, the person of the professional appears not only in the question: Who can I be for you?

Attentiveness takes place in the interpersonal space between professional and person and also shapes this space. The interpersonal space thereby becomes a place where hasty life has been slowed down or is put to a standstill. It becomes an oasis in which attention can be given to what is essential in a conscientious and precise way. Attentiveness is connected to creating the hospitality and the room in which the other can appear. Baart (2004, p. 66) says that attention is "an outreaching movement" towards the other: "it creates space and does not ask questions but invites: appear, show yourself!"

The instrumental functions of attentiveness may form the conditions for immanent goods: the social inclusion of the person through recognition and respect, the provision of comfort and the revelation of potential.

6.1.3.2 Dispositions

In the discussion of the personal characteristics of the professional, I now turn to dispositions of the good professional. A disposition can be described as a basic mindset or attitude, a psychological foundation that one intends to have as a basic principle for the professional work. A disposition can also be considered as a behavioural translation of virtues.

Open-mindedness and open-heartedness

With an open mind I refer to the quality of opening up to the subjectivity of the other. Being 'open hearted' relates to being receptive to the feelings and emotions within the subjectivity. From the narratives studied in Chapter 3 it became clear how greatly empathic sensitivity is valued. The participants spoke of sensitivity to what they feel and how they feel and sensitivity to their problems, suffering and needs. They indicated that good professionals are open and susceptible to the situation and to the experiences, emotions and needs of the person. They perceive this because the professional listens attentively and responds in a certain way. Sensitivity is also experienced because the professional ensures that there is room for emotions.

Being open-minded and open-hearted implies freeing oneself from barriers that might obstruct the perception. These might include images and prejudices associated with the situation of the person, such as a diagnosis or homelessness. It is important to gain insight into the subjective reality of the other without any judgement or preconceived notions about behaviour.

This state of mind and heart is needed to be able to expose oneself to the life world, the inside perspective, of the other. Baart (2001) uses the notion of exposure, referring to the act of opening up all one's senses to a world that is strange to one. Exposure notion consists of four stages. In the first stage, the self has to be 'oppressed'. A quick formation of opinions, or even emotional reactions, should be adjourned. So should the inclination to move into action. In the second stage, room should be created for the strange, or the other. Baart calls this 'purification'. In the third stage, the person becomes susceptible to the other. This frees the way for what Baart calls "a concrete involvement in which responsibility is taken for what is presented, and which needs compassion, effort, respect and care" (2001, p. 214). This is the fourth stage of exposure, which is the devotion towards the other, expressed in engagement, loyalty and support.

Authenticity

The narratives tell us about the importance participants attach to a professional being authentic. Authenticity is experienced as beneficial. When I explore this notion from the perspective of the professional, a first connotation is that a professional should stay in close contact with his or her own self, with what he or she feels is right, and with what can be borne or tolerated.

Although we expect a professional to reflect, learn and develop, through which his or her conceptions about what is right could change, there should always be congruency between feeling, thinking and acting. Authenticity is found in the person of the professional, not in his or her professional role. The person is the professional; the professional is *not* the person. I

emphasise this because from this study it became clear that clients foremost want a helpful relationship with a person, *not* with a professional. And they want this person to be 'real' and genuine. This was expressed multiple times with the word 'personal'. Personal was for instance related to sympathy, revealing personal information, radiating warmth and using humour.

Rogers speaks of a "congruent, genuine, integrated person": "it means that within the relationship he is freely and deeply himself, with his actual experience accurately represented by his awareness of himself. It is the opposite of presenting a façade, either knowingly or unknowingly" (1957, p. 99). This also includes that feelings that arise during contact with the client, such as fear or anger, are not denied.

Being present in an authentic way means that the whole person is there, as a fellow human being, with his or her oddness as well as his or her qualities. Being authentic also includes showing a vulnerable side. Authenticity can thereby promote equableness (see paragraph 5.3). If initially the professional is perceived as *the* authority, authenticity can show that the professional is 'less than perfect', which may promote a real exchange. This attitude includes admitting mistakes and the willingness to learn from the client.

The authenticity of the professional can also be considered an invitation to the other to be authentic, to reveal him- or herself as the person he or she really is. In the light of the reconstruction of identity, it can be regarded as an invitation to search for authenticity.

Positivity

Another disposition that came to the fore from this study is positivity. Care recipients value a positive attitude and a positive focus of professionals. A positive focus is an important aspect of constructive communication. A positive focus means a focus on possibilities, on qualities and achievements, and on the healthy side of the person. It is an expression of the belief that the situation will and can get better. It is a belief in strengths and possibilities, a focus on progression. The professional believes (has faith) in the client and believes that progression can be made. An optimistic focus opens up new perspectives. In recovery studies about people with mental illness, this is often associated with *hope* and *confidence*. Positivity is associated with optimism and makes the world lighter. Many participants said they value the use of humour. Positivity is also associated with empowerment, since one of the principles of empowerment is that everybody has possibilities to grow and develop.

For a long time, positivity has been placed in the margins of the professional and scientific arena. This might be explained by the dominance of an exclusive focus on pathology, impairments and disabilities, on the absence of health or 'normality', which apparently did not leave room for other aspects such as the remaining 'healthy' functions and the attention to the hopeful desire of patients for improvement. Positivistic science has been based on this disease model, mainly studying deficits and abnormalities, for a long time ignoring subjective dimensions.

Box 6.5 Positive psychology

Recently, the science of 'positive psychology' has been given counterweight (Snyder and Lope, 2002). Although humanistic scholar Abraham Maslow used the phrase *positive psychology* already in 1954, speaking about creativity and self-actualisation, it was not until a decade ago that positive psychology became a serious field of study in the USA, mainly through the work of Martin Seligman (Seligman, 2002; Seligman & Steen, 2005). The most basic assumption of positive psychology is that human goodness and the strive for individual and common wellbeing are as authentic to being human as disease and distress. Positive psychology examines quality of life notions such as pleasure and happiness, kindness, curiosity and hope. The central themes of humanistic psychology are returning in current research practices of positive psychology, such as the basic strive of people for developing and using their potential.

Positive psychology starts from two basic assumptions. First, positive interventions, by definition, build pleasure, engagement and meaning. Second, it is believed that building positive emotion, engagement and meaning may actually counter disorder itself (Seligman & Peterson, 2003). A number of studies provide growing evidence for these assumptions (Duckworth, Steen & Seligman, 2005; Peterson, 2006). Many of the relevant factors coming forward from these studies are traditionally called 'nonspecific factors'. However, careful consideration of these nonspecific factors reveals that many are strategies suggested by positive psychology research and theory. One such strategy is instilling hope (Seligman 1991, Snyder, Ilardi, Michael & Cheavans, 2000). Another is the building of buffering strengths such as courage, interpersonal skills, insight, optimism, authenticity, perseverance, realism, capacity for pleasure, future-mindedness, personal responsibility and purpose (Seligman, 2002). A final strategy is narration. Telling the stories of one's life and retelling them from a new perspective can be a transformative experience (Csikszentmihalyi, 1993; Pennebaker, 1997).

Being disturbable, interruptible and approachable

A final disposition is that the professional is approachable and accessible. He or she should be willing to let him- or herself be disturbed. Being disturbable has several connotations. The first comes forth from the notion of commitment. Commitment is not only practiced on the professional's own terms. Although he or she indicates the boundaries of what is feasible, the other is allowed to make an appeal to this engagement in a way he or she chooses. This might not be the way preferred by the professional.

The notions of presence and availability include what Baart (2001, p. 756) describes as "being inscribeable" or "interruptible". Professionals make themselves available and clients can "inscribe" them "with a name, a role (or relationship), a task, an expectation" (Baart, 2001, p. 756). Recipients are allowed to indicate how they can be served by the professional. The basic assumption here is that the professional is dealing with a reasonable person, who desires a reasonable relationship.[68] According to Baart (2001, p. 767), 'reasonable' means in

[68] Also compare Van Ewijk (2003).

essence that someone has good reasons to do (act, think, be, move) as he or she does and is able to explain these. It might be possible that reasonableness does not come from a rational explanation, but becomes clear from the context. Reasonableness might have to be constructed from a moral, intuitive or emotional level. Most people are able to have some self-reflection and therefore have the ability to reason. Where this ability is impaired, for example in people with severe intellectual disability or severe forms of Alzheimer's disease, at least the *assumption* of reasonableness with patience and perseverance creates a kind of reasonableness.

A second type of connotation has to do with emotional disturbance. The professional allows him- or herself to be 'disturbed' by the story of the other. Disturbance can be caused by the dramatic events the other has encountered, his or her suffering or his or her struggle. The professional lets him- or herself be emotionally touched, not having to rationalise away emotions, but simply accepting that they are allowed to be there, and that it is good that they are there, because they form an essential part of a human connection. It is also part of the concept of companionship.

Another source of disturbance can be the result of the 'difference' of the other. The other might disturb the professional with his or her nasty behaviour or distorted body. Conventional social rules may be broken or idealised images of beautiful bodies shattered.

A third connotation relates to a 'clash of cultures'. Being disturbable does also mean that one's personal thoughts and ideas, stemming from one's own cultural background, can be disturbed by the perspective of the other that stems from another cultural background.

The notion of disturbability connects to the reality of life as a collection of complex and often ambiguous phenomena. Life entails a constant interaction of factors that mutually interfere with one other. Sometimes factors build up to stability, sometimes they disturb stability. Although all biological and social systems constantly seek homeostasis, they do so because of this continuous process of interference. In this sense, disturbability can be considered a necessary disposition for every human being. But as a professional working with people whose lives are disturbed in many different ways, it especially requires an attitude of being able to deal with instability, ambiguity and interference.

Being disturbable can also be applied to the interaction between the professional and the environment, the community and the system contexts of organisations and society. However, disturbable might also have the meaning here that the professional is willing to disturb the peace, to break rules, in case this is needed for the benefit of the client.

6.1.3.3 Abilities

The notions of empathic sensitivity and responsiveness, on the basis of 'an open mind' are closely related. An open mind is necessary to use the capacity of empathic sensitivity. Empathic sensitivity is needed to be adequately responsive.

Empathic sensitivity

The notion of empathy suggests that the professional allows to be (emotionally) affected by the situation of the other. Empathic sensitivity includes being attentive and using multiple senses to sensing the subjective experiences of the other. Here I am talking about attentiveness as an ability, in the next paragraph it features as a disposition.

In ancient Greece, philosophers used the word *empatheia*, which implies an active appreciation of another person's experience of feeling. The English word empathy is derived from the German *Einfühlung*, which literally means 'feeling oneself into'. Modern conceptualisations share the idea that empathy involves the capacity to relate to the inner experience of a person. In good care, this subjectivity is not only perceived but also reflected. Professionals have to possess the ability to gain understanding, as accurately as possible, of what it is that a client is experiencing from the client's perspective, but they should also have the competence to communicate about it, and to create an atmosphere of validation and support. Empathic behaviour includes active listening, genuineness and positive regard, a sense of understanding, and accurate attunement to emotional and cognitive processes (Freedberg, 2009). Rogers describes empathy as "to sense the client's anger, fear, or confusion *as if* it were your own, yet without your own anger, fear, or confusion getting bound up in it" (1957, p. 99, my italics). In later work, Rogers refers to empathy as 'a way of being' through which the professional, without judgement, enters the private world of the client (Rogers, 1980). The professional experiences an accurate, empathic understanding of the client's perspective and is aware of his or her personal experience. It entails sensing the other's private world as if it were one's own, but without losing the 'as if' quality. This is necessary because only in this way can empathy contribute to providing a secure and safe context that validates and reaffirms the person's sense of self (Rogers, 1951).

Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen (2006, p. 87) argue that, though the professional has to connect to the subjective world of the other ('stepping *into* the shoes'), at the same time, he or she should remain *outside* of this world "to avoid being overwhelmed by his or her fears, angers, joys and hurts". Freedberg (2009) states that resonating deeply with the feelings and experiences of the client is no problem provided that the professional is able to remain closely connected to his or her own feelings. There should be keen self-awareness and the ability to maintain clear yet flexible boundaries. This is also reflected in the exposure notion of Baart (2001). Feminist relational theorists conceptualise empathy more broadly, namely as a reciprocal, dynamic process that is embedded in the relational and cultural context of the relationship between client and professional and that grows and changes over time. In an intersubjective approach, the professional is not seen as merely an object of the client's needs, but as a separate entity, whose empathic personal responsiveness allows the other to reveal him- or herself. Jordan, Walker & Hartling (2004) speak of *anticipating empathy*.

Sensitiveness requires the use of multiple senses to observe and collect information. It is related to looking and seeing, listening and hearing, touching and feeling and sometimes even smelling. It also includes using intuition. The professional is susceptible to the attitudes, feelings or circumstances of the other. Being sensitive also has the connotation of having a high degree of receptivity for impressions.

Empathic sensitivity helps to connect to the person and to acquire understanding about his or her situation, experiences and needs. It also helps to understand the 'story behind the story', or to understand the experiences expressed by the person in the context of a larger framework. This basic sensitivity also implies to maintain an openness that can also lead to emotional and aversive responses to what is experienced. The professional has to reflect on these experiences and come to terms with them.

Responsiveness

Later in this chapter I elaborate on the notion of care responsiveness, which should be continuously maintained throughout the entire care process (see paragraph 5.6.2). This responsiveness is focused on the needs of the client, but also on the responses of the client vis-à-vis the professional and the services provided. In the responsiveness process, the professional connects his or her own framework and perspective to the framework and perspective of the other. Maintaining this mode requires the open mind and the empathic sensitivity of which some features have been discussed above. I now discuss some of the capacities needed for such responsiveness. Responsive abilities are essential for establishing good connections.

Responsiveness is closely connected to sensitivity. It is the ability to respond to the other person on the basis of what is sensed. Here the professional actively reacts to what the other is expressing. The professional answers to the wishes, expectations, needs and demands of the client. The notion of responsiveness implies being flexible. The professional follows the perspective of the person, and connects this to his or her own perspective. Responsiveness does not mean that a professional should accept and allow everything that is happening. A number of participants in this study indicated that they appreciate what might be called a 'double response' – reacting with understanding (or trying to find out what is happening) and being clear about how the professional feels about it, including the indication of boundaries.

In the process of acquiring, processing and returning information, responsiveness refers to the latter two parts. The information that is collected through multiple senses is cognitively processed. The professional analyses and reflects on the information and forms an inner response. The outcome of this intrapersonal process is translated into an overt response to the other. Feedback is given, in which the understanding and recognition of the message or appeal of the client are incorporated. Depending on the content, securing and/or strengthening elements are also present in the feedback.

Responsiveness is to a large extent based on competences to realise what I have called in Chapter 4 'constructive communication' or 'constructive dialogue'. These competences include the arts of conversing, listening, asking, reflecting and communicating in understandable language. In the course of the responsiveness process, clearness is pursued:

clearness about the relationship as well as clearness about conceptions, needs, desires and actions.

In each situation, this again requires the capacity to work on multiple levels: the intersubjective level of the relationship and the level of needs and actions connected to the quality of life of the person. On the level of the relationship, the professional has to take aspects of diversity into account. On the level of needs, responsiveness is related to both objective and subjective aspects of quality of life. Responsiveness might include here aspects of dignity, autonomy and rights. Empathic responsiveness can contribute to the development and reformation of the person's sense of self and identity.

Finally, responsiveness is expressed in actions. Although the verbal and nonverbal expressions of the professional can be considered actions (acts of expression), actions that relieve problems are also an important part of responsiveness (competent helping).

A final remark about responsiveness is that this notion relates to accepting responsibility (paragraph 5.5.2.3). Responsiveness can in this light be regarded as acting in a responsible way in the relationship with the other. Surrey (1991) speaks of *response-ability*. This term refers to the abilities to react to the needs and feelings of the person.

6.2 Elements of a practice

The ethical foundation and the tenets of good care should be translated to daily practice. Besides the characteristics of the caregiver and of the position the professional takes, the discourse consists of methods or approaches that form a sound instrumental translation.

From my analysis two concepts emerged. The first one is the notion of interpersonal space. This notion is connected to the notion of a shared perspective. A shared perspective can only be created when there is reciprocal communication. Real understanding develops when there is a mutual feeling of connectedness and understanding, both on an affective and on a cognitive level. The second concept is the notion of care responsiveness, which is necessary for creating this multilevel connection.

The categorisation of the different elements of a practice of good care is depicted in the scheme displayed in Table 6.4:

Table 6.4: Elements of a practice of good care

4. Practice		
Creating and maintaining an interpersonal relational space that is supportive and helpful (paragraph 6.2.1)	*Preparing (paragraph 6.2.3.1)* *Approaching (paragraph 6.2.3.2)* *Getting in touch (paragraph 6.2.3.3)* *Sensing and understanding (paragraph 6.2.3.4)* *Affirming and accepting (paragraph 6.2.3.5)* *Creating a shared perspective (paragraph 6.2.3.6)* *Doing/acting (paragraph 6.2.3.7)* *Evaluating and learning (paragraph 6.2.3.8)*	*care responsiveness (paragraph 6.2.2)*

6.2.1 Creating an interpersonal space

A central concept in the practice of good care is the creation of an interpersonal relational space. I define this as the psychological space in and by which two people are connected. I allot two features to this space. One is that it is *interpersonal*, referring to the fact that the space is created through the interaction between two people.[69] The space is constituted by the fact that two people meet each other as equal and unequal human beings – equal in the sense that both share the same basic human features, such as being vulnerable and striving for self-reliance and growth, and unequal in the sense that both are different but unique with regard to identity, experience, knowledge and roles.

The second feature is that the space is *relational* by nature. Good care is embedded in a relationship. The space is constituted by the relationship between two people. It is not a space simply created by and for professional interventions aimed at problem solving. It is a space based on the basis of presence and the ethic of good care. Within this space a shared perspective and respect for diversity and autonomy are essential.

The interpersonal space has to be developed and cultivated. This is a process in which different phases can be distinguished. On the basis of the empirical data I distinguish the following: preparing (paragraph 6.2.3.1), approaching (paragraph 6.2.3.2), getting in touch (paragraph 6.2.3.3), sensing and understanding (paragraph 6.2.3.4), affirming and accepting (paragraph 6.2.3.5) and creating a shared perspective (paragraph 6.2.3.6). Doing/acting (paragraph 6.2.3.7) refers to both relational/communicational acts and acts of competent helping. The former takes place during all the stages, from approaching to creating a shared perspective. The latter takes form on the basis of the relationship that has been shaped. Evaluating and learning (paragraph 6.2.3.8) also refers to both the relational and the action

[69] I put the relationship between two individuals in the forefront, to exemplify the connection between a professional and a client, but this principle can be extended to a network of individuals, e.g. the client and his or her relatives and peers, and the professional and his or her colleagues.

level. It is a constant reflective action during all other stages, and is a necessary basis for monitoring responsiveness.

The psychological dimensions of the interpersonal space comprise of both affective/emotional and cognitive/rational elements. In the narratives, participants mentioned for instance 'I like this practitioner' (e.g. "he is nice", "she understands me") and 'He is a great help to me' (e.g. "he provides me with great therapy", "he solves my financial problems", "he watches over me").

The intrinsic and extrinsic value of the interpersonal relational space is expressed in the notions support and helpfulness. Being supportive has a number of different connotations, which have generally in common that the life of the other is not taken over, but that autonomy is respected and supported. Support serves as (part of) the foundation of self-reliance. The aim of support is to sustain a person, especially in times of affliction. Support can have many different forms, such as moral support, encouragement and so on. Help is also a form of support, but it is usually expressed in forms of practical assistance and specific services (such as providing therapy, budget management, domestic aid and job mediation). Support and helpfulness imply that what happens within or as a result of the interpersonal relational space is convenient and beneficial to the care recipient.

6.2.2 Care responsiveness

In the framework of interpersonal relationships, interactive responsiveness is a crucial notion. A connection that makes good care possible is only established after a professional responds to a client in a way that the appeals and needs of the client are understood, acknowledged and accepted, *and* after a client acknowledges that the professional understands his or her appeals and needs and accepts that he or she responds in terms of support and help. I condense these thoughts in the notion of care responsiveness. I first elaborate upon this notion, and then I will outline the different phases and elements of the process.

In Baart's research on the needs of people in socially marginalised conditions, he summarises these appeals in the question: "Does it matter to you that this, here, to me, always, happens in this way, hurts and should end?" (Baart, 2001, pp. 651). In Baart's theory, the emphasis seems to be placed on the moral appeal to the professional to show that the situation of the other really matters to him or her. This corresponds to Question 4 of my clustering in Table 4.9 in Chapter 4: 'Do you acknowledge and reaffirm me?' 'Does it matter to *you*" refers to the individual appeal made to the professional as a person, not to a mere representative of an institution. In all the questions this emphasis is reflected: Who are *you*? Can *you* be trusted? Are *you* someone with whom I can feel safe? Are *you* someone who really understands me? Do *you* acknowledge and reaffirm me? A productive connection is established when these questions are answered, from the perspective of the person, in an affirmative way. Then, the person is *care responsive*.[70]

[70] Madeleine Timmermann (2010) has demonstrated in a study about the care in a nursing home for people with dementia that needs can also be expressed non-verbally, for example by crying or lamenting. The perspective which is revealed here is characterised by pain or cold and a cry for help which demands to be acknowledged. The study shows the importance of constant relational fine-tuning.

I would like to use these insights to refine the notion of care receiving as developed by Tronto (1993). I would like to place much more emphasis on the way in which care intentions and actions are perceived and responded to than Tronto does. I share the criticism of Van Heijst (2005) that Tronto's model suggests more agreement between caregiver and care receiver than often exists in reality. Differences in position are not problematised. It is necessary to pay more attention to what care receivers experience, what they think and how they judge the provided care.

From the analysis of the data from my study, it seems that clients especially value the responsiveness of the professional and respond positively to this responsiveness. They were responding to a great extent to the sensitivity of the professional, which also has a strong affectionate component. Responsiveness is composed of different elements, which I describe in more detail in the next sections

The construct of good care is much more dynamic than it appears from the work of Tronto. This might be explained from the conception of care as a practice orientated mainly towards specific results, neglecting the importance of care as a process. From a process perspective, the interaction between a caregiver and a care receiver receives more attention. The recipient already responds to the way in which the professional responds to his or her signals and messages from the first moment the two meet. The attentiveness of the care provider is not only focused on the need for care as a 'product to be delivered', but also on needs connected to recognition, comfort and so forth. The attentiveness of the recipient is also focussed on the way in which the professional cares or, in other words, expresses care-fulness.

When I consider the components mentioned by Tronto as *reciprocal* notions, they become much more significant. Attentiveness, responsibility, competence and responsiveness from the side of the recipient are as important as from the side of the professional. They work both ways, and therefore become embedded in a mutual interaction. This could be depicted in the conceptual scheme in Table 6.5 below, in which care receiving is placed on a vertical axis instead of a horizontal one, expressing that in all the components of the practice the response of the care receiver is important.

Table 6.5: Transforming Tronto's care receiving into the concept of care responsiveness

Care as practice	*Virtues*	*Care receiving (responsiveness)*
Caring about or observing a need for care	*Attentiveness*	Perceiving and expressing that the professional is sensitive to (all) the needs
Taking care of, or organising to relieve needs	*Responsibility*	Perceiving and expressing that the professional is responsive to the needs, proposing the right type of support Taking the responsibility to collaborate and making an active contribution
Care giving or direct provision of care	*Competence*	Perceiving and expressing that the professional is able to deliver the needed help Experiencing that the care provided (or shared action) restores or increases personal competence

Care receiving is composed of different elements: it is the response to the caregiver with regard to his or her susceptibility to the needs of the person (often experienced as expressed in an empathic and understanding way), and to the actions the caregiver undertakes with regard to meeting the needs. The response of the recipient consists of three components: perceiving, expressing and acting.

Adding the element of acting places the recipient in the role of an active participant in his or her own care process, instead of a person who depends on the actions of caregivers. Good care can only be realised in the context of an interrelation and interaction. The interaction takes place on both a communicational level and a practice level. Good care includes equality and collaborationship. In the process of care, recipients have a responsibility of their own to make an active contribution. Good care is aimed at recovery: restoring or increasing the personal competence.

As I have discussed, recognition is an important part of this process. In the reciprocal notion of care responsiveness, the recognition by the care recipient of the caregiver is equally important. Van Heijst (2005, p. 177) states as follows:

> "The person in need of care remains someone who can abstain or give recognition, and that ability is a feature of human dignity. The person receiving care and recognition is herewith put in the position to be able to give something. Not on command, but in freedom."

6.2.3 Phases/dimensions

The phases (or dimensions) mentioned in Table 6.4 are refined in the following table:

Table 6.6: Components of the practice of good care

Phases of good care	*Care as practice*
Preparing (paragraph 6.2.3.1)	Adapting and internalising the principles and values of good care
Approaching (paragraph 6.2..3.2)	Becoming present in the life world of the other
Getting in touch (paragraph 6.2.3.3)	Being present: connecting to the personal context
Sensing and understanding (paragraph 6.2.3.4)	Understanding appeals, meaning, vulnerability, strengths and (consequent) needs
Affirming and accepting (paragraph 6.2.3.5)	Acknowledging the appeal, accepting and expressing the responsibility for responding to the appeal
Creating a shared perspective (paragraph 6.2.3.6)	Co-creating a common framework of understanding and action
Doing/acting (paragraph 6.2.3.7)	Competent helping with two main elements and aims: securing and strengthening
Evaluating and learning (paragraph 6.2.3.8)	Monitoring care responsiveness and the results of the care process; reflection and learning from experiences

The overview shows that in the care process, some steps precede the phase of observing a need for care. On the part of the caregiver, I have added one element that precedes or underlies the others. I call this 'the preparedness for care-fulness'. By this I mean that the professional enters a caring relationship on the basis of moral and ethical principles, a vision of how to deliver services belonging to the logic of good care, and the characteristics as described in paragraph 5.5.1. I presuppose that a certain disposition is needed (a basic professional frame of reference founded by a logic of good care), which is used to approach and connect to the other.

Only after a connection has been established, the (beginning of the) formation of an interpersonal space, are the other steps possible. Approaching, connecting and understanding require attentiveness. In the care for people in complex vulnerable positions, the observation of a need for care is based on a thorough understanding of the personal meanings of the other, their biography and social environment, their specific vulnerability, but also their strengths. Response from the side of the professional includes affirmation of the appeal that has been understood, and acceptance that something has to be done about it, and that the specific professional is the one who is going to do something. In Tronto's concept, responsibility is connected to the actual care provision, while I would like to classify

it just one step before the actual help is provided. Although affirming and accepting can be seen as separate acts, I have placed them together to symbolise the transition from the phases of establishing a relationship and an understanding, which are part of the creation of the interpersonal space, to the actual commitment and actions of the professional.

A final phase or dimension is evaluating and learning. Since care is a dynamic process that requires constant adjustment, reflection and learning are indispensable. Good care, although it generates instantaneous goods (see next paragraph), is dependent on a constant effort to check whether the efforts lead to beneficiality or can be improved. Learning by experience is important for the professional and for the person in his or her development process.

I will now discuss the different components of the phases that have been described, integrating the principles and values described above. I emphasise that the phases do not constitute a strict linear model. Therefore I also use the word 'dimension' to indicate that they are all parts of a dynamic entity. Although there is a chronological line from preparing to evaluating, the model is not meant to be a 'stepped care' approach. Although preparing can be seen as the first step, the other phases and its elements develop in a dynamic way. Evaluating and learning take place during the entire process.

6.2.3.1 Preparing

I define preparing as adapting and internalising the principles and values of good care. On the one hand, this includes acquiring theoretical knowledge about the discourse unfolding here, i.e. knowledge about the different tenets I have discussed. On the other hand, it concerns the development of basic qualities proven relevant in this discourse. Not all preparations can be done 'in advance'. They will mostly be done throughout a continuous learning process, in which reflection and skills development are important elements. Another aspect following from the tenets is that in each new situation, with every new person, an open mind is required.

The theory of presence pays much attention to the basic disposition a professional needs in order to provide care (Baart, 2001). Making oneself available and becoming susceptible to the other is a personal process of the professional him- or herself. Baart includes dimensions that are related to the institutional context the professional belongs to. An 'open agenda' can only be achieved if a professional frees him- or herself from standard routines imposed by institutional structures or developed over the course of professional socialisation. A professional should 'disarm' him- or herself to be able to stand frank and free before the other. Here there is a parallel with the notion of dialogical deconstruction as developed by Heymann (2001). She states that the professional should 'deconstruct' the burden of knowledge and habits to an extent that an open dialogue becomes possible. This deconstruction also includes being aware of current premises of the modern concepts of man and world, which heavily influence (and hinder) interactions between professionals and clients.

Obstacles that might be in the way should be removed. Obstacles might be preconceived conceptions about the other (in psychiatry this could for instance be the features of a particular diagnosis) or about the nature of the relationship between a professional and a client (e.g. the expert versus the helpless). Obstacles might also be the requirements of the

care system (such as delivering a certain specified 'service' within a pre-determined timeframe). The core is that the professional becomes approachable, 'touchable' and 'interruptible' by the other. All the senses are opened to be receptive for as many different impressions as is possible. By hearing, seeing and feeling all kinds of information are received. All this information should be processed on both a cognitive and an emotional level. This mode of working inevitably causes surprises, both pleasant and unpleasant.

The logic of good care implies that the professional commits him- or herself to attune to the perspective of the other. This also implies taking responsibility for acting upon the needs coming to the fore in the next phase.

Finally, the professional prepares for what I call *care-fulness*. This notion has a number of connotations:
1. The professional prepares for full commitment to the person, intending to provide what is needed and to do this in the best way possible, using all resources available.
2. The professional wants to take the person to the full, with his or her entire being and problems included. Care-fulness also refers to the notion of full citizenship.
3. The professional wants to be care-ful in the sense of being cautious, precise, attentive, and watchful.

6.2.3.2 Approaching

Approaching expresses the movement towards the other. The professional wants to come near the person and become present in his or her life world. He or she looks for ways in which to establish contact. This is not just a physical exercise, but also, and foremost, a mental and communicational endeavour, which takes into account the vulnerable situation and the personal niche of the client. In Chapter 4, I listed a number of elements that can be part of the approaching process, such as availability, time and establishing contact. A number of these elements correspond to the findings the studies about presence (Baart, 2001; 2007c. The basic intention is to be(come) committed. This includes wanting to become involved in a relationship with the other. It is a conscious choice. An open way of approaching includes having an open mind, being susceptible to the story of the other and for the way his or her life and situation are presented, without restrictions. One becomes present by being present. Being present does not mean *a priori* that the other wants to be engaged, but that all the conditions are created to give opportunity to do so.

Essential in this phase is the way the professional presents him- or herself as a person wishing to be present in the life of the other. There may be many different ways to do this, but a common feature is that is a rather *unprotected* way of offering oneself. From my study it seems important that professionals can take an independent position, so that they are not hindered by identification with an institution. Thereby the space can be created that is necessary to be really committed to the client.

6.2.3.3 Getting in touch

Getting in touch means making the step from becoming present in the life world of the other to being present. A connection with the personal context is established. In the narratives analysed in Chapter 3, participants talked about experiencing 'real contact'. This was often associated with sympathetic feelings, e.g. "I saw he was touched by my story".

Others spoke of a 'click' to indicate that a connection was made. Getting in touch is a reciprocal event. To touch requires the other to permit to be touched. In some of the narratives in Chapter 3 this had taken quite some time. Participants had isolated themselves in a cocoon, surrounded by a defence system, often to protect themselves from new experiences of disappointment. In many cases it took the professionals a long time of loyal presence to be allowed to enter the inner world of the other.

From my analysis it is learned that three elements contribute to connection. The first element has to do with care responsiveness: participants indicated that a connection is constituted by experienced availability, time, attention, feelings of respect, equality, empathy, commitment and dedication, a flexible moving along and continuity in the relationship. The second element concerns communication. I have called this constructive communication to indicate that the communication of the professional constructs a positive framework for reciprocity and development. Aspects of constructive communication are dialogue, asking, listening, being clear, openness, sensitiveness, responsiveness and positive focus. The third element can be considered the result of the former two. This is the room, or interpersonal space, that is created, which in itself is the expression of the connection between professional and client. The interpersonal space provides an adequate space for interaction, and offers the frame for understanding and the other phases that follow.

Box 6.7 An active-passive mode

In the connecting process, the professional operates in an 'active-passive mode'.
In the theory of presence Baart (2001, p. 754-757) has described a number of working principles.

1. Freeing oneself, or: letting oneself be freed
2. Opening one self, or: letting oneself be opened
3. Involving oneself, or: letting oneself be involved
4. Inserting oneself, or: letting oneself be inserted
5. Moving oneself, or: letting oneself be moved
6. Lending oneself, or: letting oneself be lent
7. Controlling oneself, or: letting oneself be controlled
8. Devoting oneself

Except for the principle of devotion, Baart divides both an active as a passive form, by adding the verb 'letting'. Letting implies exposing and surrendering oneself to the experience, just undergoing what is happening. This often requires an effort, because in general, people want to be in control, and one of the most important socialisations of professional behaviour is to remain in control.

Working in an active-passive mode seems paradoxical. On the one hand, the professional should refrain from controlling and working from predetermined structures, while on the other hand, he has to do this in a way that is concisely described, demanding a lot of discipline and concentration. But the bottom line is that a relationship is developed that provides multiple options for support. Another aspect of this passive-active mode of working is that the professional *depends* on the other. Although Baart does not elaborate on this, the notion of interpersonal space, which relies on interdependence, is certainly present in his theory. He formulates this as creating "a podium to appear on" (Baart, 2001, p. 684). The professional opens him- or herself for the other, but is dependent on how the other will respond. He or she can be 'inserted' by the other, but this remains up to the other. This is interesting, because it implies that the positions are equal, and that reciprocity is needed to make a connection. What is also interesting is that it corrects beforehand the imbalance of power between a caregiver and a care receiver. Now, the care receiver first has to give something to the caregiver (permission to come near, to become part of his or her life) in order to enable the care provider to 'do his or her job'. On a communicational level, from the start it is an *interaction*. Although in the phase of 'being prepared' and 'being committed' to care a professional acts 'on his or her own' to move him- or herself to a position to become accessible, certainly from the phase of 'identifying care' onwards, the action does not come only from one side. Interaction is needed to put the players on the same phase.

The active-passive mode is also visible in the way the professional operates during the entire care process. It is a modest, non-intrusive way of working, leaving much of the initiative to the other. This is contrary to an interventionistic way of working. Baart speaks in this context of a "lasting uneasiness" (2003, p. 82), which has to be accepted as an inevitable and even desired feature of professional work. Since care is basically about humans 'touching' each other, and its meaning is found in dealing with the complexity and irrationality of both human existence and social systems, it cannot be reduced to mere technical procedures.

6.2.3.4 Sensing and understanding

In a narrow sense, a professional wants to understand the need for professional care of the other. In the discourse on good care, however, a broader conception of understanding comes to the fore based on the study's data, which show that participants value understanding of them as a person and understanding of their situation and their experiences, including their needs and desires. Needs cannot be excluded from the context of the person and his or her life world.

I use the word 'sensing' because it expresses that multiple *senses* have to be used, and *sensibility* and *sensitivity* are required. This is needed to acquire a *full* understanding. This understanding is an essential cornerstone for a caring relationship. Support is already generated by the experience of feeling understood. *In* the understanding the established connection is deepened and grounded. *By* understanding an adequate response in the form

of specific acts can be realised in the next phases. In the story and the situation of the other, worries and needs are revealed.[71]

The presence approach emphasises the importance of getting to know the perspective from within. This is included in the tenet of creating a shared perspective (paragraph 5.4.2). This requires the ability to put oneself in the experiential world of the other. This personal perspective, the individual and social reality as perceived and constructed by the person, should be taken 'as a whole', and not be fragmented into small parts, 'overruled' or 'disowned'. This does not mean that the inner perspective that is presented is consistent or logical. One of the postulates of the presence approach is that ambiguity is a given fact. There will always be more interpretations, there is never one truth, there will always be 'good' and 'evil'. Accepting ambiguity is an important principle. A core element of the presence approach is that confusion can be just shared instead of distancing or immediately trying to find solutions.

The inner perspective can be better understood if the social context is known as well: the apartment where someone lives, the street, neighbours and family members. Baart also emphasises working as much as possible with existing social systems. A fundamental question is to learn to understand the meaning of the story. Baart (2001, p. 756) calls this "to reconstruct local reasonableness and logic". What's the point? What are guiding ideas? What are in this perspective hindrances or chances?

The moral component of this attitude is to choose (and to hold) the position from which the professional follows this perspective (see paragraph 5.5). The basic commitment of the first phase has to be confirmed. A standpoint has (again) to be taken with regard to the perspective of the other. Do you want to choose his or her side? Of course it is also possible to withdraw. It could be that the needs that are identified are much more demanding than the professional can handle, or that the demand is in conflict with the ethical values of the professional, which is a dilemma that has to be considered and requires moral deliberation.

6.2.3.5 Affirming and accepting

This phase involves two actions, namely affirming and accepting. With affirming the appeal that is made to the professional is recognised and acknowledged. The appeal is often composed by several elements, as summarised by Baart in the sentence: "Does it matter to you that this, here, to me, always, happens in this way, hurts and should end?" (Baart, 2001, p. 651). As mentioned in paragraph 5.6.2 this corresponds to a large part to answering the question: "Are you acknowledging what is happening to me?"

By responding to the appeal, also responsibility is accepted. The professional 'inserts' himself in the perspective of the person, thereby also confirming a shared perspective and committing him- or herself to act upon it. Affirming and accepting the appeal require an

[71] An interesting study has been conducted by Pols (2005), who looked ethnographically at the care for people who do not speak or hardly speak. She proves that it is indeed possible to understand the situation and desires of these people by carefully observing what they do in their daily life and what they like and dislike. Instead of taking verbal communication (opinions, narratives) as a source of information, appreciation as it is enacted in an *in vivo* situation are analysed: "Instead of the subject being an active, autonomous and authentic individual with a perspective on the world, the subject becomes a *co-production*, a result of interactions with others and a material world" (2005, p. 211).

understanding and affirmation of *what* has happened or is (still) happening, and of the person and his or her experiences. Affirmation is also related to respect. From my analysis it appears that affirmation is related to recognition and acknowledgement: of suffering, needs and desires, of personhood, of the value of experiences, knowledge, talents and achievements. These are forms of valuation and validation (see paragraph 5.4.4), which also contribute to the reconstruction of identity and the development of autonomy.[72]

6.2.3.6 Creating a shared perspective

In the basis of the previous phases, within the interpersonal space a shared perspective is (further) developed. This is done on the basis of constructive communication or dialogue. The communication from the side of the professional so far had the objective to create a relationship and to understand the position of the other. At certain moments in this dialogue, the opinion of the professional is also brought in, an opinion that is based on the observations and reflections of the professional, and is (also) fed by his or her body of knowledge. At this point it is crucial that the perspective of the other is sufficiently understood and acknowledged. This is the tenet of shared perspective in which it is essential that the basic appeals of the other are left intact.

Creating a shared perspective is a condition and a regulative basis for the next phase of competent doing/acting. There are two main parts in this perspective. The first one is that there is common understanding of and agreement on what is at stake. The second one is a dialogue about what should be done. Creating a shared perspective also implies that in the course of the process personal perspectives may change, since interaction between people always influences the own perspective.

Developing a shared perspective is a form of co-creation of knowledge. It can be considered a common learning process, in which the participants learn with and from each other (Van Biene, 2005). The 'personal wisdom' of both person and professional is brought together in one conceptualisation. Whether this conceptualisation will lead to successful actions remains to be seen, but is a basis from where to start. Furthermore, the shared perspective will keep developing (and changing) during the entire process. Through monitoring and evaluating, learning will continue. This learning process can be regarded as valuable by itself.

A particular aspect of the shared perspective is constantly searching for conceptions of what should be, or is, 'good' or 'beneficial'. Mol (2008, p. 75) states: '[…] what is to do good, what leads to a better life, is not given before the act. It has to be established along the way. […] In the logic of care, defining 'good', 'worse' and 'better' does not precede practice, but forms part of it."

[72] From this study and other studies (e.g. Bohlmeijer, 2007a/b; Hoogenboezem, 2003; Petry & Nuy, 1997; Verkerk, 1999) it seems that a narrative approach method can be a powerful form of support in the process of identity validation.

6.2.3.7 Doing/acting

Doing what should be done, or acting, refers to offering support and help in a competent way. By putting this in a separate phase, I do not mean that in the other phases a professional does not act. On the contrary, all the phases require actions, regardless of whether it is about realising presence or gaining understanding. Here I refer to the actions that are meant to offer an adequate response to the needs which require professional care. Providing adequate care requires competent helping. On the basis of my analysis, I conclude that this should be aimed at two main aims: securing and strengthening. Securing is a response to (physical, psychological and social) vulnerability, which requires ensuring sufficient safety and the management of a personal niche that helps to keep self-control, and serves as a basis for a social life (see also paragraph 5.5). Strengthening is a response to the desire to become stronger: to be able to cope better with the disability and with environmental factors and to recover and to develop talents and skills in order to fulfil meaningful roles and activities.

How is care provided? In the presence approach care or support is mainly provided in the very act of sharing. In this context, the professional is 'lending' him- or herself as a person, doing things with or on behalf of the other. In these provisions, a certain reticence is preserved. Things are not just taken over. There is an emphasis on the own strengths and the own actions of the other. This also means that the professional inserts him- or herself in the time perspective of the other. People may need time to orientate, to work things through, to have doubts and to take decisions.

From my study it is evident that this way of working is valued by clients, although sometimes in retrospective. Again, this does not mean that everything happens in a slow mode. When necessary, for example in an urgent situation, quick efforts are made to solve problems or to bring relief. A logical consequence of the relationship between the professional and the client is that care workers offer and care receivers use their potential. In Baart's (2001) study, this potential includes for example their language skills, the information they have and their access to the world of welfare and care. In my study these potentials also included psychotherapeutic skills, knowledge of medication and access to housing and jobs. In both studies, professionals often fulfil the securing function of being an anchor point. They offer a safe spot, someone to attach to in a safe way. They offer reassurance. Another function is to use the professional as a 'window to the future', an orientation point to develop new perspectives, a vista to another future or identity.

An important aspect is that professionals allow clients to define how they want to use their assets. This is the notion of 'inscribableness'. The professional is assigned a role, a task, an expectation. The big difference from classical care provision is that the client is in charge, directing the professional to be used in such a way that it will benefit him or her. Of course, this requires a subtle interplay revolving around the normative stand of 'good use'. The professional is not just a tool to be used, but has a responsibility of his or her own, searching for agreement between the conceptions of the client and the own personal and professional norms, matching possibilities and limitations. This is all part of the shared perspective to be created. Operating as a normative-reflective professional is essential (Jacobs *et al*., 2008).

Finally, part of the action is aimed at the environment. This might be aimed at gaining access to resources or improving the quality of network support. From the narratives in Chapter 3 it appears that this sometimes requires trespassing rules and procedures in a sensible way. Doing/acting is always framed in the context of the social and system world.

6.2.3.8 Evaluating and learning

A final part of the process of good care concerns evaluation and learning. As is the case with the other parts, this is not a separate process. It goes on and on during all the phases. By evaluating and learning, a connection can be established, understanding can be obtained and deepened, and actions can be improved. In addition, the results of the care process are evaluated: Does it lead to the desired outcomes?

Since the notion of care responsiveness is important in the logic of good care, a precise and constant monitoring process is required. Monitoring includes the way in which the person responds to the presence of the professional and his or her acts of expression and support. It also includes self-monitoring: following and evaluating the own intentions, attentiveness and responsiveness to the client. The experienced benefit of the client should be evaluated. Evaluation may result in adjustments. These might be adjustments in terms of relationship, activities, services or the quality of the process. The professional constantly mirrors the practice against the background of the six tenets and the excellence that is pursued. The main question remains whether the professional is still in a 'good care mode', contributing to the wellbeing of the other by offering support that is complementary to the needs of the individual and his or her personal and social resources.

In the light of *shared perspective*, thinking and acting, it is interesting to note that developing personal knowledge is also important at the side of the client. Part of the process of recovery is to explore the knowledge embodied in past experiences, and to transform tacit knowledge into overt personal knowledge that can be used to affirm the identity, to understand events and to develop a future perspective.

6.3 Summary and epilogue

In chapters 5 and 6 my objective was to contribute to an emerging theory of good care. I constructed a discourse in which an ethical foundation, basic theories, objectives, practice and characteristics of good care as embodied by professional care providers are described. This discourse was developed on the basis of insights that could be derived from studies on recovery in general (Chapter 2) and my own empirical study (chapters 3 and 4), which had as a special focus the values attributed to professionals by people in the position of client, and which could be derived from the analyses of the narratives.

The logic of good care is embedded in a theory of ethic of care. Building on the work of Tronto and other scholars such as Baart en Van Heijst, I put forward that good care is embedded in a dialectical relationship that is based on human dignity and the wellbeing of people in a vulnerable position. This vulnerable position is always regarded as caused by a combination of personal and social factors. Within the relationship, the notion of care responsiveness is important. Care responsiveness connects the care provider and care recipient. The professional is sensitive towards the narrative of the person, tries to gain full understanding of the person and his or her perspective, and responds and is attuned to his or her expressions. One of these expressions is the needs and desires that came to the fore in the narratives. Good care contributes to the acknowledgement, support and development of identity and autonomy. My study underlines the importance of the theory of recognition as developed by Honneth with the three key elements of love, respect and solidarity.

On the basis of this ethic of care, six fundamental tenets of good care can be distinguished, namely presence, shared perspective, diversity, recognition, autonomy and vulnerability, and empowerment. Each of these areas can be considered separate theoretical frameworks, although they are interrelated. Further research is required to study the precise relationships between the tenets. My assumption is that they are all of equal importance. Ignoring one of them will weaken the foundation of good care. I approach these areas as *tenets*, indicating that in each unique practice[73] the challenge is to use these frames and to discover how they can be applied.

In the practice of good care, basic qualities can be narrowed down to a sound ethical basis that provides the integrity to be there for the other (with preservation of the own position), to respect diversity and to support the other in improving quality of life (expressed in restoring or fortifying identity, taking care of vulnerability and increasing autonomy). Because all these elements should be included in good care, it requires a thorough awareness. A professional should be fully prepared to work this way. Care provision should be fully charged with these notions. I call this being prepared for *care-fulness*.

In order to be 'care-full', the professional wants and has to establish a personal-professional connection, dedicating himself and his knowledge and access to resources to the benefit of the person. He should also have the communicational and relational competences to establish a relationship. In this process, understanding and recognition are key notions. Through understanding and recognition, the other can be affirmed on the levels of the identity, the needs and the desires. The two main practical acts of the practice of good care are securing and strengthening.

[73] I follow the definition of MacIntyre (1985, p. 187). See foot note 29.

All the elements of good care have combined meanings. They are at the same time social, psychological, symbolical and physical or practical by nature. The way in which the professional behaves and expresses him- or herself can be considered as *acts of expression*. What is appreciated as supportive by the participants in this study is the expression of understanding, faith and hope. It is the expression of hearing the basic appeal, which is often hidden beneath the surface and has to be excavated and heard. It is the expression of the value of the other.

These expressions are formed and take place in what I call the *interpersonal relational space*. This is the psychological and social space that constitutes the connection between the person and the professional. In this space it is essential that the professional knows and respects the *personal niche* of the other. I reserve this notion for the psychological and physical space a person needs to take care of the frailty connected to his or her illness and/or disability. The quality of the interpersonal relational space, which is the basis for different kinds of care and support, is determined by the process of *care responsiveness*. The interpersonal relational space is characterised by reciprocity and mutual dependency, or interdependency. Both parties depend on each other, which is not a negative but a positive asset. It calls upon a journey to find each other in a constructive way, a process of constructive communication or dialogue.

What is essential in this process from the part of the professional is that he or she should constantly monitor how the person reacts to his or her acts of expression. The crux of a productive collaboration is that the other perceives the presence of the professional as being supportive and (potentially) beneficial. The concept of care responsiveness requires a great deal of perceptiveness and sensitivity. Responsiveness is not only expressed in verbal communication but also in nonverbal communication. The professional constantly attunes him- or herself to the other and his or her environment. In order to be(come) a responsive professional, the working principles of Baart (2001) are valuable. These comprise of the following: letting oneself be freed, be opened, be involved, be inserted, be moved, be lent and be controlled.

Essential ingredients for establishing a connection as revealed by this study are closely connected to these principles: authenticity, a positive disposition, being committed and dedicated, being loyal and benevolent, being attentive, being interruptible and being approachable. If the connection process is successful, which can be measured by a person indicating that he or she is sympathetic towards the professional and expressing relaxation and trust, a *partnership* can develop. This partnership might have traits of friendship. Figuratively the professional can be placed in, and accept, the position of friendship.

The ultimate aims of good care are physical, psychological, social and existential by nature. Physical and psychological aims concerns offering security, encouragement and hope and increasing strengths and possibilities. The professional offers this (already) in the relationship itself, and uses the relationship and the actions that are a response to needs and aspirations as a means or bridge to connect the person to him- or herself and the world (extending social participation). In the relationship this is done by offering companionship and attachment. By the social nature of good care it can contribute to recovery, since, as

concluded in Chapters 2 and 3, this process is largely mediated through social processes. In this social process, recognition and acknowledgement are of great importance. Good care helps the other to reveal and affirm his or her personal identity and values.

Good care is offering a bridge between the person and the world, either in a narrow sense, such as the connection with family, neighbours or a workplace, or in a broad sense, such as the connection with society or being acknowledged as a full citizen. In this respect the professional not only acts as a fellow human being, but also as a fellow citizen. He or she symbolically represents the world, and can act as a bridge between the world of the person and the world at large.

The ultimate aim of good care, seen from the perspective of the community and the society, is social inclusion. I have argued that social inclusion requires a culture in which the elements of good care are reflected. Social inclusion requires respect for differences and the willingness of every citizen to remove barriers and to create room for each other's vulnerability and to value strengths and contributions to social capital.

Honneth's theory of recognition offers an excellent framework by relating the notions of identity, vulnerability and autonomy to each other, including the connection Honneth makes with social exclusion and inclusion. In love we recognise the acts of attachment and the provision of basic trust and security as a means to contribute to a unique identity. Good care is based on the sympathy for another human being and compassion with the tragedies he or she experienced. Respect for the other, in all of its aspects, contributes to restoring autonomy, which is connected to self-determination and awareness of rights. Solidarity can be connected to valuation and the promotion of self-esteem. It is also connected to the notions of dedication and commitment, of staying present and offering sustainable support. Finally, recognition can in my view be connected to empowerment, since it offers the foundation for recovery, personal development and increased wellbeing.

Summary

The book consists of six chapters. After an introductory chapter, the results of a systematic review of recovery studies over the past 15 years are presented in Chapter 2. The chapter starts with a summary of the data of 15 longitudinal studies conducted between 1969 and 2001. Thereafter, a review of 27 qualitative studies published between 1993 and 2009 is presented. The chapter concludes with the results of a cluster analysis.

In chapters 3 and 4 the results of a qualitative empirical study, based on the analysis of 13 narratives, are described. This study was conducted among people with (long-term) mental health care experiences in the Netherlands, focusing on both their personal story and their conceptions about what effectively helped them in their recovery process. The aim of this part of the study was to find out what happened to them in terms of life events and their mental disorder, how the person dealt with vulnerability, and what the role of the environment was. I was especially curious to find out which factors hindered or facilitated progress. Within this analysis there was a special focus on the role of mental health care. What services did the participants perceive to be helpful? What is considered by the participants to be 'good care'? Chapter 3 describes aspects of vulnerability and recovery that came to the fore from the analysis. In Chapter 4, the results of a secondary analysis are presented. In this analysis I searched for essential notions in the interaction between the narrators and professional caregivers. I investigated themes in the stories that were associated with good care.

In Chapter 5, the insights of this narrative study are developed into a theory of good care by connecting these findings to other relevant studies and theories. In Chapter 6, a translation is made from theory to a practice of good care.

Chapter 1

Chapter 1 describes the objectives, background and methodological design of this study. The objectives of this study were the following:

1. To contribute to knowledge about recovery and professional support for recovery.
2. To contribute to a theory of good care (for vulnerable people) on the basis of an ethic of care.
3. To contribute to practices of good care by eliciting essential elements of good care.

For decades, scientific and professional practitioners have studied, written and spoken *about* people with mental illness. Over the past decades, the influence of 'consumers' in both practice and research has increased considerably. Under the influence of the rehabilitation and recovery movements, their personal experiences are now increasingly being heard. Their position has changed from that of passive object to active subject. They have moved from the role of a patient, client or consumer into the role of an expert-by-experience, a co-researcher or a peer specialist. A new type of (scientific or at least grounded) knowledge is sprouting: experiential knowledge that complements other scientific sources. For professional practice, it puts the relevance and importance of personal experiences and the conceptualisation of the person involved about his or her present and future situation in the centre of interest.

This is the reason why I decided to conduct an empirical qualitative study by collecting and analysing narratives of people who have experienced or are still experiencing serious mental health problems. Besides learning about factors hindering and facilitating recovery, I wanted to learn from their experiences of professional services. I was convinced that by thoroughly analysing data from a 'client's perspective', evidence could be found of factors that really contribute to health and wellbeing. For the research design, I decided to collect evidence on the basis of the experiences of service users only, and not from professionals, in order not to 'contaminate' the experiential data.

This study is qualitative by nature. Empirical data were used for conceptual analysis, using the methodology of grounded theory. Grounded theory is a qualitative research approach that enables the eliciting of new insights into phenomena and novel theoretical formulations from data (Glaser & Strauss, 1967).

Chapter 2

In Chapter 2, I reviewed two types of studies on recovery: first, the 'traditional' longitudinal studies, which are mostly focused on objective measures such as symptomatology and functioning, and second, the modern qualitative experiential studies, which are mainly focused on subjective experiences. The chapter starts with a summary of the data of 15 longitudinal studies conducted between 1969 and 2001. Thereafter, a review of 28 qualitative studies published between 1993 and 2009 is presented. The chapter concludes with the results of a cluster analysis.

Longitudinal studies

The course of severe mental illnesses has already been studied for more than a century. These studies mostly had a clinical angle. Recovery was perceived in a medical sense, although social dimensions were also taken into account. Many longitudinal studies have been conducted, especially until the eighties of the last century (e.g. Ciompi, 1980a; Strauss & Carpenter, 1974a;b; Strauss *et al.*, 1978). In the first sections of Chapter 2, an overview is given of longitudinal studies on the course of schizophrenia and other diagnoses of long-term psychiatric disorders. Although different definitions of recovery are used, generally the studies investigated the reduction of symptomatology and improved social functioning. The conclusion was that throughout the century, a significant proportion of people showed a considerable reduction of symptoms and/or improved social functioning. On average, longitudinal studies show that over the years, a greater percentage of people with serious mental illness recover. From a large meta-analysis conducted by Harrison *et al.* (2001), which included more than 1 600 people from over 10 countries in Asia, Europe and North America, it was concluded that a significant proportion achieve favourable long-term outcomes. Global outcomes at 15 and 25 years were favourable for over half of all people followed up. Striking heterogeneity was seen across the different dimensions of outcome. A baseline diagnosis of ICD-10 schizophrenia was consistently associated with poorer outcomes in symptoms, social disability and resource utilisation. Despite marked variations across cultural settings, the absolute mortality risk for people with schizophrenia and related psychoses is high and remarkably similar in all the countries examined. The best predictor of all outcome measures was the duration of psychotic symptoms experienced in the two years following onset. The shorter the duration of psychotic symptoms, the better the longer-term symptom and disability scores as well as the overall course of illness.

More recent studies show that a combination of efforts made as quickly as possible after a psychosis develops for the first time may significantly reduce the time needed for symptomatic recovery, thereby also influencing favourable social recovery (e.g. McGorry *et al*., 2008). Important factors seem to be the prevention of hospitalisation or the reduction of hospitalisation to the minimum; the organisation of adequate support from the social network; and the provision of good medication, education, counselling and supportive out-patient mental health care services.

Experiential studies

From the late eighties of the last century onwards, a growing number of personal accounts were published. People started writing about their own recovery process. From the nineties onwards, scientists and professionals became increasingly interested in the phenomenon of personal recovery, and conceptual writings started to appear. Over the past 20 years, a growing number of studies that collected the experiential knowledge of people in many countries have been published. They mostly include an analysis of personal narratives and use a grounded theory approach to develop ideas about phenomena related to recovery, the course of a recovery process and factors influencing the course. I selected 28 different studies that included more than 950 subjects in 11 different countries.

A serious mental disorder can be caused by different biological, psychological and social factors. It causes numerous serious disturbances with which a person has to deal. Among these disturbances are a disturbed perception; attention deficits; loss of ego boundaries and sense of unreality; disturbed thinking; and disturbances in emotions, relationships and behaviours. The impact of mental health problems on people's social lives is often highly disruptive, and includes the disruption of relationships with partners, children, parents and friends. Many people report a severe impact on their career or potential career. In addition, stigmatisation is a major problem. Actively seeking and gaining control over the psychiatric experience are important steps in the recovery process. But furthermore, people have to deal with the environment, whether it is the environment of a mental health care service, the social network or the community.

A number of studies show patterns of a recovery process. Generally speaking, recovery is a developmental and reconstructive process from the onset of the illness, often accompanied by a state of serious crisis and disintegration of the self, leading either to a state in which the person knows how to cope with the illness and its consequences or to a total recovery (defined as the absence of the illness). During this process, two parallel processes evolve: a process in which the person has to come to terms with him- or herself, and a process of reconnecting to the world. Reconnection is a word that describes well the focus of both processes. These people have to reconnect to themselves, find their core identity and take control over their disability and their own life. They also have to reconnect to the world around them: their social network, the school, the neighbourhood, the job.

The actual recovery process entails three phases. In the first phase (stabilisation), the main task is to gain control over the illness itself. In the second phase (reorientation), an important task is to develop an explanatory framework for understanding the experience of an illness and to develop a positive future perspective. The person resolves to start working on psychological recovery. This stage involves taking stock of the intact self, and of one's values, strengths and weaknesses. It may involve learning about mental illness, services

available or recovery skills, or becoming involved in groups and connecting with peers. The person works to build a positive identity. This involves setting and working towards personally valued goals, and may involve the reassessment of old goals and values. This stage involves taking responsibility for managing the illness, taking care of disabilities and taking control of one's life. It involves taking risks, suffering setbacks and coming back to try again. This is the preparation for the third phase. In the third phase (reintegration), the person moves into roles that are meaningful, productive and valued by the larger society.

During this process, changes are marked by turning points or transitional stages. I identified different types of transitions. The first is the transition at *rock bottom*, when people decide that this situation is no longer liveable and has to change. In many studies, it is shown that the starting point of recovery is often a situation of great despair. A second type of transition is made when people enter a comprehensive *treatment and rehabilitation programme*, which helps them to get a grip on their situation and encourages them to move forward towards recovery. A third type of transition is marked by (an increasing) *sense of agency.* This refers to the moment people take charge of their illness, their recovery process or their life in general. This is often accompanied or preceded by insight or self-acceptance. The fourth type of transition occurs later in the process, when people seem to have adjusted to the disability to a degree that they feel strong enough to make a *change in one of the social domains* of living, work, education or relationships.

An analysis of factors that contribute to recovery resulted in five clusters, which together form a multidimensional model:

1. Factors that provide personal motivation to initiate recovery and to move forward
2. Factors contributing to the reconstruction of the identity
3. Factors belonging to the development of competency for coping with the illness and the environment
4. Factors of social engagement
5. Environmental factors that serve as resources for recovery

Motivational factors that belong to the first cluster are, among others, having the desire to contain the illness and its consequences, wanting to create meaning and to make positive life changes and being hopeful, believing recovery is possible. Factors that belong to the second cluster of developing identity are, for example, segregating symptoms and environmental factors from personhood, assigning meaning to past experiences, discovering personal strengths and incorporating illness into a (new) positive identity. Developing competences for coping with the disability, the third cluster, include learning skills for coping with the illness and its consequences, developing competences to put life and identity into (a new) perspective and developing self-care and social skills. Factors that contribute to shifting the social status and (re)engaging in the community, the fourth cluster, include engaging in meaningful activities, engaging in social roles and engaging in positive relationships. A fifth cluster contains environmental resources such as supportive relationships, material resources (housing, income) and mental health care resources (e.g. medication, psychotherapy, counselling).

Mental health care services should be responsive, which means that services should adequately and flexibly respond to the needs of the person. In case hospitalisation is

needed, this should be in a safe and friendly and the least restrictive environment. Services have to contribute to increasing competence in coping with vulnerability and life stress, and to exploring issues of identity.

The presence and support of professionals is important – professionals who genuinely care, have positive expectations and a positive and encouraging way of working, and who allow enough room for expression, self-direction and self-development. Professionals who validate people's experiences, respect them, believe in them, focus on their strengths and believe in their potential are appreciated. On a practical level, professionals who recognise the need for assistance, make (extra) efforts on behalf of the person, give adequate and effective advice and provide good-quality services are valued.

In the interaction within clusters, and in the interaction between factors in different clusters, changes occur that may lead to progress or decline in a recovery process. Change may occur in all of the clusters. It can happen within one cluster, and influence the factors in one of the other clusters. It can also happen simultaneously as a result of events in other clusters. It seems that over the course of time, a transition is made when a number of factors from different clusters are strong enough. Recovery can be regarded as a spiral *development process*. The (clusters of) factors mutually influence and reinforce one another. For example, the development of social skills (competence) boosts self-confidence (motivation). By getting positive feedback (social support) while engaging in a social role (shifting social status), empowerment of the self is increased (motivation) and courage is strengthened to undertake new actions/interactions.

The relationship between intrinsic and extrinsic factors and the relationships between motivation, competences and social participation require more research. It is still not clear how different elements in a recovery process come together over the course of time. It is assumed that for each individual the composition is different. If the different elements *synchronise*, for example meeting the right support person at the right time when a person is susceptible to make a change in life, then development takes place.

In the process of recovery, the notion of *empowerment* seems to form a golden thread. It can be connected to all the clusters. The process can be characterised by continuous and growing empowerment. By acquiring competences, empowerment is enhanced. As a result of the empowerment of the self, transitions can be made towards meaningful activities and social roles. The support of material and personal resources empowers the person and thereby contributes to his or her recovery process.

The goal of empowerment becomes one of people gaining power and control over their lives through access to meaningful choices and the resources to implement those choices. The findings document the crucial role that *choice* plays in empowerment. Having information on and access to a range of meaningful and useful choices and options fosters recovery. People are empowered when they make choices regarding where to live, finances, employment, personal living / daily routine, disclosure, who they associate with, self-management and treatment. For such empowerment to occur, meaningful options must exist and people may need training and support in making choices. Too often, quality-of-life choices seem outside the realistic reach of many people. Options are limited, of poor quality

or nonexistent. Participants recounted service providers, professionals and family members and communities that responded through the use of coercion, control and restricted access or involvement, discrimination and stigmatisation.

Recovery is a personal and social process that takes place in a strictly individual timeframe. How fast or how slow this process goes, is fairly unpredictable. From the studies it becomes clear that too much external time pressure may harm the process. Environmental support should be finely tuned to the stage of the process and the needs connected to what is important for the person in this particular stage by looking at which (cluster of) factors could be strengthened.

Chapter 3

In chapters 3 and 4 the results of a qualitative empirical study among 13 people with (long-term) mental health care experiences in the Netherlands, are described. What happened to them in terms of life events and their mental disorder? How did the person deal with vulnerability, and what was the role of the environment. What services did the participants perceive to be helpful? What is considered by the participants to be 'good care'?

For most of the participants in this study, recovery was an ambivalent notion. Many of them did not speak about recovery as such, but used different terminology. The process of recovery was connoted for example as a process of *struggle* and *survival*; a process of *finding balance*; a process of *discovery*; and a process of *recreation* and *reintegration*, both internally in terms of reconstruction of the identity and externally in terms of becoming part of the social world again.

It is clear that recovery is not a linear process, but that it is characterised by instability, moving back and forwards, with ups and downs. In its temporality, recovery is generally long term in nature, although there is much variety. In my study, some participants seemed to have moved to a phase of reintegration within one or two years, others indicated that this had taken them 10 years or more. The same variety was demonstrated in terms of pace. Sometimes changes occurred rapidly; at other times it took several years. The results support many of the findings of the review in Chapter 2.

Apparently there are two sub-processes that constitute recovery. One is the process of *personal recovery*, which I call 'recovery of the self', or the process of personal (re)integration. This sub-process consists of two main tasks: (1) gaining control and taking care of vulnerability; and (2) developing identity. This leads to (more) self-control, and to a stronger or more integrated identity. The other sub-process is the process of *social recovery* or the process of social (re)integration. The task here is to work on social integration: becoming part of society. The outcomes of the first sub-process are awareness of personal assets (experiences, knowledge, skills, talents, aspirations) and competences to take care of personal vulnerability. The outcomes of the second sub-process are participation, valued social roles and meaningful activities.

The phases (stabilisation, reorientation and reintegration) and transitions in the recovery process, as described in Chapter 2, can also be recognised in the narratives in this study. The process of recovery is a constant process of *interaction*. Interaction has two elements:

interaction with the self and interaction with the social environment. My analysis supports the findings of Ochocka *et al*. (2005), who consider a successful 'negotiation' between these two types of interactions as critical for recovery.

The interaction with the self can be characterised as a self-dialogue, in which finding a meaning for what has happened (the crisis, the disease, the trauma) and coming to terms with these facts are central themes. All the narratives in this study show this. The process of constructing or reconstructing the narrative seems to be crucial for development. Part of the narrative is to understand the *vulnerability* itself. Understanding what it is and how it works makes it easier to find a way to handle different consequences of the vulnerability. From my analysis the notion of *the personal task* emerges. The personal task can be defined as the daily struggle the person has with his or her own impairments; the attempt to keep a balance in order not to 'go under' or to 'go out of one's mind'. It is a task someone has to perform him- or herself, but external support is often needed, for example in the form of medication or a 'watcher' – someone who helps the person by keeping an eye on him or her.

I introduce the notion of *personal niche*, which I define primarily as a psychological zone in and through which a person feels reasonably comfortable and remains in a state of balance. It is a constellation of mechanisms of self-regulation with regard to stress and energy management. A personal niche is individual and unique to the person. It is a protected environment that is safe and offers security to the person. It is owned and directed by the person him- or herself and is 'non-interruptible', in other words an environment that no other person should enter. The personal niche also has physical and environmental dimensions. The physical dimension is related to stress as experienced by psychiatric symptomatology such as delusions and hallucinations, or physiological phenomena such as headaches, and can also be induced by external factors that cause stress. Within the personal niche, stress is absent or reduced to an acceptable level. Physical wellbeing includes being able to get enough rest or sleep and the absence of anxiety or depression, or these being present at a manageable level. It often requires active physical and psychological efforts to maintain a balance. Environmental aspects include physical surroundings such as having a primary territory like a room or an apartment that can be fully controlled by the person, and the positive influence of external factors such as support from other people. Participation in social environments should match as much as possible with the requirements of the personal niche.

Discovering and determining the personal niche and gaining insight into how to take care of vulnerability is an important form of individual development. When vulnerability is adequately taken care of, it means that the possibilities to participate in meaningful social activities and roles increase. From the narratives it appears that once someone is able to handle his or her personal niche, this provides a foundation for shifting the social status.

The other element of interaction is interaction with the *social environment*. Social resources are needed for many different purposes. They serve as support in the processes mentioned before: the process of coping with crisis, surviving, identifying and managing the vulnerability; the process of finding rest and stability; the process of discovery and creating a personal narrative; and the process of recreation of the identity and reintegration into meaningful activities and social roles. In this regard, other people act as support pillars. In

the narratives, many different kinds of supporting people are mentioned, such as family members, peers and mental health care professionals.

For the sake of recovery, many people use environments that provide safety, social contact, support and recognition. These may be environments in the domain of living, working or socialising. I use the concept of *social niche* to characterise these types of milieus. These are social environments that are adapted to or do not intervene with the requirements of their personal niche. In a social niche, the personal limitations (or in other words the necessary conditions for social participation) are acknowledged, providing room for meaningful social functioning. An optimal situation seems to be one in which on the one hand, the personal niche is respected, and on the other hand, valued social participation is realised on the basis of interests, talents and skills.

Most of the niches the participants in the study used were created by mental health care agencies; however, 'peer environments' also serve as social niches. There is a difference between the more vulnerable people, whose 'personal niche' comprised a great sensitivity to stress factors, and the less vulnerable people, whose personal niche was much easier to manage. In the latter category, social relationships were less complicated to handle and their social network was much larger. The former group used more facilities offered by mental health care agencies, while the latter group used more consumer-run initiatives.

The narratives in this study reveal a number of external elements that are valuable resources. These elements can be divided into personal and material *resources*. The participants in this study were or had been using different types of environments that were relevant to their recovery. I found three types of environments in the narratives: natural environments, peer environments and mental health care environments. However, in many narratives, participants also talked about environments that caused stress and were damaging. It also became clear that the relationship between the personal niche and social environments is often an ambiguous one. On the one hand, people need social relations for a number of reasons, while on the other hand, these interactions cause stress and may be potentially risky. Facilitating environments serve as resources for basic needs such as housing and socialising. They provide opportunities for activities and social roles. They serve as places for reorientation, affirmation and development.

A physical personalised space, such as an apartment or a room, is an important 'home base' for securing safety within the personal niche. Personal belongings, but also pets (who often offer valuable company and support), can be part of these physical arrangements. As in other studies discussed in Chapter 2, the importance of having decent housing, adequate financial means and the social security system also came to the fore in this study.

In the participants' stories they talked about the social and psychological factors that had meaning for them. In terms of social factors, they spoke about the importance of belonging to a community of people and of being at a specific place (such as a day centre, a work place, a building where a meeting of a multilogue group is held). Sometimes, in these places, there was a personal relationship, sometimes there was only a connection by the mere fact that other people were participating in the same environment. Simply the feeling of being connected in one way or another, even if it is only through membership of a certain

community, gives a sense of belonging, which is important in the process of social reintegration.

Social support is an important factor for recovery. It can be offered by an individual or in the context of a particular environment, for example a working environment or the environment of a mental health care setting. Besides the social niches provided by mental health care and social agencies, the networks of family, friends and peer support or recovery groups appear to be important support systems.

It can be concluded that there are two categories of support. One is *temporary support with a high impact*. This type of support addresses an urgent need, for example the need to be comforted, to be heard or to solve a pressing problem. The other category is *long-lasting support*. The data analysis revealed that there are indications that continuity of people around the person is an important factor. Continuity is expressed by people not breaking the relationship and staying in touch. In many cases family members fulfil this role; however, professionals with a long-term relationship are also considered highly supportive. The mere presence of people in both bad and better times seems to be an important support factor. On a psychological level, these relationships provide recognition, acknowledgment and thereby hope. They also provide a connection to the world and help the person with reintegration. An important finding is that the person has to perceive the relationship as adequate with regard to what is needed, including the needs related to the personal niche. Besides the actual presence of others, apparent availability is also regarded as adequate support. This means that it is valued that others are accessible and can be approached if needed.

Looking at factors that contribute to *empowerment*, both intrinsic and extrinsic factors could be determined. Extrinsic motivational factors may lead to increasing intrinsic motivation. From my analysis it seems that relevant individual factors are the survival of a crisis situation, a certain goal orientation, enough self-confidence, enough physical and mental energy, and the belief someone has in his or her own possibilities. These can all be considered inner strengths. Positive (real-time) experiences, for example the experience that a task or job is performed successfully, contribute to empowerment. All these factors also contribute to the development of a new sense of self as an integrated entity or, in other words, to the (re)constitution of the personal identity. Relevant external factors that are important sources to be able to move forward are others who provide support, hope, encouragement and opportunities to change living conditions, including material resources such as housing and financial means. A specific factor is acknowledgement. This entails the recognition that one is (still) a human being, an individual with a personal identity. An element of this recognition is the acknowledgement of personal qualities such as talents, skills and performances. Associated with this is the (growing) belief that life is meaningful, and that there is a future-orientated perspective.

In the domain of *mental health care*, valuable resources are, among other things, medication to which the person responds well, safe environments and professionals who engage in a personal relationship in combination with providing support that is considered by the person as helpful. Professionals are perceived as helpful when they succeed in making a connection on a relational level. An important finding is that interaction characterised by a

trustful relationship is in itself a cherished resource. These professionals have a way of relating to the person so that the person feels that he or she is seen and understood. Being seen and understood can relate to different things: the suffering, a particular problem, a need. An aspect of understanding is that there is consideration of the feelings and the emotions attached to the problem or hidden under the surface.

Professionals who have a more long-term involvement make three mayor contributions. Firstly, they play an assistant role in the management of the personal niche. Secondly, they play a role in development, for example of the identity and of skills. They keep on supporting the process of orientation by providing hope, setting goals, making plans and realising ideas. They help the person to increase his or her strengths and to develop skills and talents. Thirdly, professionals play an important role with regard to social recovery – the reconnection to the world. They help in the process of reintegration, for example by supporting the person to enter new environments and roles.

Chapter 4

In Chapter 4, the results of a secondary analysis are presented. In this analysis I searched for essential notions in the interaction between the narrators and professional caregivers. I investigated themes in the stories that were associated with good care. I define good care as care that is perceived by a receiver of care as 'beneficial'. These themes were categorised into five categories: connecting, understanding, affirming, securing and strengthening. The categories are characterised in terms of active verbs, to indicate that they relate to an active and dynamic process.

The first category entails the establishment of a personal connection. Although it is a separate category, consisting of a number of elements, the connection can only develop and obtain meaning through the acts within the other categories. Connecting can be regarded as a process that may start with a glimpse of sympathy for the professional that deepens over the course of time. Sympathy can be evoked by the empathic attention the professional gives, by the respect he or she shows or by the humour he or she uses. Deepening of the relationship can develop due to reciprocity in the relationship, through dialogical conversation and a continuing presence and through acts of commitment and dedication. The connecting process may result in a feeling of togetherness or companionship. The relational and communicational notions that were identified create a so-called *interpersonal space*. This is a psychological and metaphorical notion that expresses a number of qualities that are needed for constructive collaboration and for supporting recovery in a beneficial way. In this safe space there is room for being, room for expression and dialogue, and room for development. It seems that a connection and collaboration between professional and client are only established if there is a kind of reciprocity or responsiveness from both sides.

The second category refers to the person feeling understood. This can be an understanding of the situation or of him- or herself as a person. Feeling understood strengthens the personal connection with the professional. The notion of understanding is connected to the sensitivity of the professional for the personhood of the other and his or her situation and experiences. The person feels understood on the basis of the being and expressions of the professional. The professional also contributes to a better understanding

by the person him- or herself. This can be done by letting the person tell his or her story, by asking clarifying questions and by helping to put experiences in a larger perspective.

Another important act is that the person has the experience of being acknowledged. This constitutes the third category. Again, this may be an acknowledgement of the personal situation, but also of vulnerability and strengths. By this recognition the person feels seen and respected. I have chosen the term 'affirming' to express that by being recognised and acknowledged (especially), people in vulnerable dispositions experience something to hold on to. Being recognised as a unique human being means that one's personal identity is revealed and affirmed. At the same time, it is an expression of value and an important element to increase self-confidence. The notion of affirming has a threefold meaning. The first is that the professional answers to the need of the person to be recognised as a worthwhile human being, with a personal autonomy and a unique identity. The second is that the person's personal experiences and knowledge are acknowledged (as being valid and valuable). The third meaning is that the professional expresses that he or she attaches him- or herself to the other and expresses engagement and support. The personal–professional connection is affirmed, also from the side of the client.

The fourth category is securing. Although affirming is also a form of securing, securing encompasses all elements that help the person to feel safe (or safer). From my analysis it became clear that the mere presence of a professional who is trusted by the person and who offers companionship provides the needed safety. Different active forms of securing came to the fore in the study. This varies from a quick response to a desperate phone call to setting up an early warning-sign or crisis plan. The attachment between professional and client provides a form of security, which answers to the need of feeling safe and of having someone to hold on to. Within the act of securing, other, more specific elements are also visible, such as assistance to take care of the personal niche and the offering of reassurance. The professional may also serve as a form of 'social insurance' by offering companionship.

The fifth category is called 'strengthening'. From this study there is overwhelming evidence that good care is aimed at making people stronger and helping them in their recovery or development process. Strengthening starts with recognising the strong (healthy) side of the person and focusing on possibilities. Clients value professionals who have an optimistic point of view, who provide encouragement and inspiration. An important form of strengthening is supporting people to learn from past and present experiences. One might say that securing, understanding and affirming are the basis of a supportive relationship. Although this helps the person to feel connected, to feel recognised and to feel safe, which in itself are basic human needs, this may not be enough for recovery. From the perspective of the participants in the narratives, acts of strengthening should also be added. Here the professional helps with the three fundamental tasks of recovery: reconstructing identity, increasing skills to take care of the vulnerability and restoring autonomy and social participation. Important empowering acts seem to be discovering the core identity by learning from experiences, emphasising talents and achievements, offering inspiration and encouragement, working on a future perspective, and connecting people to environments that offer space for growth.

Chapter 5

In chapters 5 and 6, the insights of the previous chapters are developed into a theory of good care by connecting them to other relevant studies and theories. A discourse is constructed in which an ethical foundation, basic theories, objectives, practice and characteristics of good care as embodied by professional care providers are described. This discourse was developed on the basis of insights that could be derived from studies on recovery in general (Chapter 2) and my own empirical study (chapters 3 and 4), which had as a special focus the values attributed to professionals by people in the position of client, and which could be derived from the analyses of the narratives. The categories of professional support expounded in Chapter 4 are placed in a discourse of good care.

In Chapter 5, an ethical foundation and six tenets are presented. The objectives of good care are also described. This is followed in Chapter 6 by depicting aspects of the position of both caregiver and care receiver and describing elements of a practice of good care.

Ethical foundation

The logic of good care is embedded in a theory of *ethic of care*. Building on the work of Tronto and other scholars such as Baart en Van Heijst, I put forward that a practice of good care is embedded in a dialectical, reciprocal relationship that is based on human dignity and the wellbeing of people in a vulnerable position (Baart 2001; Tronto, 1993; Van Heijst, 2005). In this relationship, recognition is essential (Honneth, 1995). The relationship is based on presence and the recognition of the other as a fellow human being (equality) *and* as a unique, special individual (inequality). In this ethical frame, frailty is acknowledged and conserved. The practice revolves around the recognition and restoration of human integrity and human dignity. Good care is both aimed at the preservation of vulnerable people as well as on inclusion and empowerment. The caring relationship revolves around the discovery of what is considered 'good'. In the conception of the good, it also becomes apparent what value should be strengthened, supported and obtained.

Tenets

On the basis of this ethic of care, six fundamental tenets of good care can be distinguished, namely presence, shared perspective, diversity, recognition, autonomy and vulnerability, and empowerment. Each of these areas can be considered separate theoretical frameworks, although they are interrelated. Further research is required to study the precise relationships between the tenets. My assumption is that they are all of equal importance. Ignoring one of them will weaken the foundation of good care. I approach these areas as *tenets*, indicating that in each practice (as defined by MacIntyre, 1985) the challenge is to use these frames and to discover how they can be applied.

The core of the tenet of *presence* is to become and to be present in such a way that this beneficiality is experienced. The tenet of presence is to become, to be and to remain present in a way that provides a dedicated connection with a person. The tenet requires that ways are found to come close, to be attentive in an open but intense mode and to relate to the life world of the person (Baart, 2001). This requires calmness, sensitiveness and loyalty. It requires of the professional to be open to the experiences and emotions of the other, and not to avoid it or push it away. It requires an effort to connect to the person on multiple levels, to be compassionate, to recognise what is at stake, and to do what should be done.

The mere presence of the professional, as typified by the mentioned characteristics, already contributes to affirmation, safety and strengthening.

The tenet of creating a *shared perspective* is related to the categories of connecting and understanding. This notion is meant to provide a way of thinking and working, which enables the connection of the two perspectives of professional and client. Good care can only be conceived through dialogue between the perspective of the person and the perspective of the professional. The tenet of shared perspective seeks to create the interrelational space of a common understanding. The core of shared perspective thinking is that the professional is able to change (in) his or her position to (understand) the perspective of the other. This serves three goals. One goal is to really understand the client and his or her needs. The second is to be able to create a relationship in which good care is possible. The third goal is to see oneself, as a professional, from the position of the other. This enables one to monitor behaviour through its effects on the other. Achieving a shared perspective can be realised through a process of discovery and learning. From this study it is apparent that this process by itself is already an important part of good care. Thus, working on the creation of a shared perspective is both *part of* and a *condition for* good care.

The exposure to the perspective of the other and the attempt to understand imply being confronted with a world that is often quite different from the personal world of the professional. This poses the tenet of *diversity*. The core task here is that the client *is* and *can be allowed* to be different, and that this difference is *kept intact*. The role and position of a care recipient are different from those of a professional. There may be differences in gender, age, cultural background, religion, skin colour and so on. I also consider a different biography, coloured by experiences with a serious disease, disabilities and the (mental health) care system, as an important aspect of diversity. I use insights from Kal (2001), Van Heijst (2005), Ghorashi (2006) and Meininger (2007) to elaborate on issues related to the recognition of alterity.

The tenet of *recognition* means seeing and affirming the other as a worthwhile fellow human being, and acknowledging his or her experiences, needs and desires. To be able to offer recognition, a professional has to understand the person and his or her situation and be sensitive to the needs connected to recognition. I use the work of Honneth (1995) to discuss different elements of recognition. Honneth distinguishes three forms of recognition, namely *love*, *respect* and *solidarity*. Honneth offers an excellent framework by relating the notions of identity, vulnerability and autonomy to each other, and makes a connection with social exclusion and inclusion. In love we recognise the acts of attachment and the provision of basic trust and security as a means to contribute to a unique identity. Good care is based on the sympathy for another human being and compassion for the tragedies he or she experienced. Respect for the other, in all of its aspects, contributes to the restoration of autonomy, which is connected to self-determination and awareness of rights. Solidarity can be connected to valuation and the promotion of self-esteem. It is also connected to the notions of dedication and commitment, of staying present and offering sustainable support. Finally, recognition can be connected to empowerment, since it offers the foundation for recovery, personal development and increased wellbeing.

The tenet of *autonomy and vulnerability* builds on the tenet of recognition. Good care contributes to the preservation and restoration of autonomy. Autonomy can be conceived as (re)attaining self-direction. It is related to the notions of control, agency and responsibility, according to which human beings are conceived as the agents of their own life and as responsible actors in the human community. From the narrative study it is apparent that autonomy and dependence can be there at the same time. Because of their specific disability, people might well trust part of their autonomy to others. The main feature attributed to autonomy seems to be that (finally) people themselves are the ones in control of decisions. Good care leaves people in control and restores the ability to exercise control as much as possible. This conception of autonomy is based on respect for human dignity and freedom of self-determination *and* on the notion of interdependence. It takes both strengths and vulnerabilities into account. Especially the latter is important when severe disabilities impede human dignity and self-determination. In my study, and also in other studies, autonomy is specifically found in the affirmation of a strong self, a self who has struggled (or is still struggling) with the disease, but is or has proven to be able to live a 'normal life' *with* the illness and the disability. Being able to overcome certain consequences of the vulnerability reinforces autonomy. In this sense, autonomy is an emancipatory notion. Autonomy is also related to social inclusion. It can only be realised if people allow each other to participate as valued, respected and contributing members of society. Social inclusion calls for the validation and recognition of diversity as well as recognition of the commonality of lived experiences and the shared aspirations among people.

Increasing capacity to take care of the vulnerability, the development of an autonomous identity and increasing social participation as forms of increasing autonomy can also be regarded from the tenet of *empowerment*. For the professional, this tenet refers to helping the person to become stronger, both individually and in collaboration with others. The tenet requires a good understanding of concepts and mechanisms of power and powerlessness within the caring relationship, in the life world of the person, in the health system and in society. I used notions of Jacobs (2001), Van Regenmortel (2002) and others to clarify this tenet. Within the relationship between professional and client, good care is aimed at equalising the power balance. The relationship that develops in the interpersonal space should provide the client with opportunities to become stronger and more powerful. Powers should be recognised and made visible, correctable and developable. I here used the notion of *mutual power*, which is aimed at the development of empowering relationships (Freedberg, 2009). Power is not something that is a given fact, but an *expanding commodity*, something that is developed in the collaboration between different parties (Israel *et al*., 1994).

The role and contribution of professional care may differ, but a common orientation can be characterised by certain aspects. The first is that the professional not only considers deficits and problems, but also positive aspects, such as the person's abilities and lessons learned from experiences (good and bad). The professional's role in making the person stronger may refer to the person gaining health, coping better with the illness or having increased self-confidence and social skills. The second is that the professional uses encouraging communication. He or she articulates the values that he or she observes and encourages the use of personal strengths. The third aspect is that in the actions of the professional there are always strengthening elements. The professional's actions are aimed

at reinforcing the client, either directly or indirectly, by creating facilitating resources. An aspect of an empowering approach is to help the person to connect to 'empowering environments' in the community. The tenet of empowerment requires that good care is not only aimed at an individual level, but also at an organisational and a community level. Empowering care also includes the creation of social niches and gaining better access to and control over resources. In this regard, professionals can function as intermediaries or bridges.

Objectives

The *ultimate aims* of good care are physical, psychological, social and existential by nature. Physical and psychological aims concern offering security, encouragement and hope and increasing strengths and possibilities. The professional offers this (already) in the relationship itself, and uses the relationship and the actions that are a response to needs and aspirations as a means or bridge to connect the person to him- or herself and the world (extending social participation). In the relationship this is done by offering companionship and attachment. The social nature of good care can contribute to recovery, since, as concluded in chapters 2 and 3, this process is largely mediated through social processes. In this social process, recognition and acknowledgement are of great importance. Good care helps the other to reveal and affirm his or her personal identity and values.

Good care offers a bridge between the person and the world, either in a narrow sense, such as the connection with family, neighbours or a workplace, or in a broad sense, such as the connection with society or being acknowledged as a full citizen. In this respect, the professional not only acts as a fellow human being, but also as a fellow citizen. He or she symbolically represents the world, and can act as a bridge between the world of the person and the world at large.

The ultimate aim of good care, seen from the perspective of the community and the society, is social inclusion. I have argued that social inclusion requires a culture in which the elements of good care are reflected. Social inclusion requires respect for differences and the willingness of every citizen to remove barriers and to create room for each other's vulnerability, to value strengths and to value contributions to social capital.

Chapter 6

In Chapter 6 I discuss aspects of the position of both caregiver and care receiver, and describe elements of a practice of good care.

Characteristics

In the practice of good care, basic qualities can be narrowed down to a sound ethical basis that provides the integrity to be there for the other (with preservation of the own position), to respect diversity (seeing the other as being different but not crazy, acknowledging suffering and vulnerability, recognising knowledge and competences) and to support the other in improving quality of life (expressed in restoring or fortifying identity, taking care of vulnerability and increasing autonomy). A thorough awareness of all these elements are necessary for good care. It requires a professional attitude of wanting to establish a personal–professional connection, and of dedicating oneself and one's knowledge and access to resources to the benefit of the person. The professional should also

have the communicational and relational competences to establish a relationship. In this process, understanding and recognition are key notions. Through understanding and recognition, the other can be affirmed on the levels of the identity, the needs and the desires. The two main practical acts of the practice of good care are securing and strengthening.

All the elements of good care have combined meanings. They are at the same time social, psychological, symbolical and physical or practical by nature. The way in which the professional behaves and expresses him- or herself can be considered *acts of expression*. What was perceived as supportive by the participants in this study is the expression of understanding, faith and hope. It is the expression of hearing the basic appeal, which is often hidden beneath the surface and has to be excavated and heard. It is the expression of the value of the other.

The basic relational configuration for good care can be characterised as *partnership*. Care recipients conceive good professionals as people with whom they can form an alliance. Important notions here are symmetry, reciprocity and interdependence. Professionals can take different positions. A valued position is companionship or friendship. This metaphoric position expresses the value clients attribute to a professional who is near to them, who is personally engaged and is willing to engage in a reciprocal relationship. The position expresses the intention of wishing a good life for the other. Another aspect of the identity is the professional as citizen. This position can be a foundation for friendship, and it enables the promotion of equality and connects the person to the community.

Since good care has a normative foundation it is important that a professional is able to reflect on what is experienced in practice. I used here the concept of the normative–reflective professional as developed by Kunneman (1996) and others. A central question in the discourse on good care is: Is what I am doing as a person and a professional beneficial to the person I am serving? In order to answer this question, conceptions of beneficiality and quality of life should be reflected upon. These conceptions are formed by norms and values of professional and client, but also of the community and the society.

Three types of qualities of the professional can be distinguished. The first are *virtues* composed of commitment and dedication, benevolence and attentiveness. The second are dispositions such as open-mindedness and open-heartedness, authenticity and positivity. Another disposition is being disturbable, interruptible and approachable. The third type of qualities is abilities. Besides the competences belonging to the profession, these are empathic sensitivity and responsiveness.

Practice

The ethical foundation, tenets and objectives of good care should be translated to daily practice. Besides the characteristics of the caregiver and of the position the professional takes, the discourse consists of methods or approaches that form a sound instrumental translation.

From my analysis two concepts emerged. The first one is the notion of interpersonal space. This notion is connected to the notion of a shared perspective. A shared perspective can only be created when there is reciprocal communication. Real understanding develops

when there is a mutual feeling of connectedness and understanding, both on an affective and on a cognitive level. The second concept is the notion of care responsiveness, which is necessary for creating this multilevel connection.

The *interpersonal relational space* is the psychological and social space that constitutes the connection between the person and the professional. In this space it is essential that the professional knows and respects the personal niche of the person. The interpersonal relational space is characterised by reciprocity and mutual dependency, or interdependency. Both parties depend on each other, which is not a negative but a positive asset. It calls upon a journey to find each other in a constructive way, a process of constructive communication or dialogue. The quality of the interpersonal relational space, which is the basis for different kinds of care and support, is determined by the process of *care responsiveness*.

In the notion of *care responsiveness*, I place the care receiver in the position of *actor*. From the side of the caregiver it concerns the response to the susceptibility of the professional with regard to the needs of the person (often experienced as expressed in an empathic and understanding way), and to the actions the caregiver undertakes with regard to meeting the needs. What is essential in this process from the part of the professional is that he or she should constantly monitor how the person reacts to his or her acts of expression. The crux of a productive collaboration is that the other perceives the presence of the professional as being supportive and (potentially) beneficial. The concept of care responsiveness requires a great deal of perceptiveness and sensitivity. Responsiveness is not only expressed in verbal communication but also in nonverbal communication. The professional constantly attunes him- or herself to the other and his or her environment. In order to be(come) a responsive professional, the working principles of the theory of presence are valuable (Baart, 2001). These principles are letting oneself be freed, be opened, be involved, be inserted, be moved, be lent and be controlled.

Eight phases

Methodically, the practice of good care can be expressed in eight phases. Since these phases are more complementary and cyclical by nature, they can also be considered dimensions of the practice.

The first phase is *preparing*. The professional adapts and internalises the principles and values of good care. I call this 'the preparedness for care-fulness'. By this I mean that the professional enters a caring relationship on the basis of a full understanding of moral and ethical principles, a vision of how to deliver services belonging to the logic of good care, and the characteristics as described. This notion also has the following connotations:

1. The professional prepares for full commitment to the person, intending to provide what is needed and to do this in the best way possible, using all resources available.
2. The professional wants to fully acknowledge the person, with his or her entire being and problems included.
3. The professional wants to be care-ful in the sense of being cautious, precise, attentive and watchful.

In the second phase, *approaching*, the professional becomes present in the life world of the other. Approaching expresses the movement towards the other. The professional wants

to come near the person and become present in his or her life world. He or she looks for ways in which to establish contact. This is not just a physical exercise, but also, and foremost, a mental and communicational endeavour, which takes into account the vulnerable situation and the personal niche of the client.

In the third phase, *getting in touch*, a first connection is established. Getting in touch means making the step from becoming present to being present in the life world of the other. A personal connection with the person and his or her environment is established. In this phase, an interpersonal relational space is created.

This connection enables the professional in the fourth phase to *sense* the person and his or her situation, to use all his or her sensitivity and perceptive abilities, to explore appeals and meaning and to assess vulnerability, needs and strengths. In this phase, the professional tries to understand all of this, and expresses this *understanding* to the person.

In the fifth phase, *affirming and accepting*, the professional acknowledges the appeal of the other and accepts the responsibility for responding to the appeal by expressing engagement and commitment. Although affirming and accepting can be seen as separate acts, I have placed them together to symbolise the transition from the phases of establishing a relationship and an understanding, which are part of the creation of the interpersonal space, to the actual commitment and actions of the professional. The acts in this phase are based on the notion of recognition.

In the sixth phase, a *shared perspective* is *created*. This is the process of co-creating a common framework of understanding and action. At this point it is crucial that the perspective of the other is sufficiently understood and acknowledged. There are two main parts in this perspective. The first one is that there is common understanding of and agreement on what is at stake. The second one is dialogue about what should be done. Creating a shared perspective also implies that over the course of the process, personal perspectives may change, since interaction between people always influences the own perspective.

Creating a shared perspective is a condition and a regulative basis for the seventh phase, which is competent *doing and acting*. The professional adequately helps the person by using his or her knowledge, talents, skills and resources. The support consists of actions belonging to securing and strengthening. Securing is a response to (physical, psychological and social) vulnerability, which requires the ensuring of sufficient safety and the management of a personal niche that helps to keep self-control and serves as a basis for a social life. Strengthening is a response to the desire to become stronger: to be able to cope better with the disability and to develop talents and skills in order to fulfil meaningful roles and activities.

Finally, the eighth phase is *evaluating and learning*. Since care is a dynamic process that requires constant adjustment, reflection and learning are indispensable. Good care, although it generates instantaneous goods, is dependent on a constant effort to check whether the efforts lead to beneficiality or can be improved. This includes the monitoring of care responsiveness and the results of the care process. Learning by experience is important for

the professional and for the person in his or her development process. The professional (and the person) learn from experiences by reflecting and looking for improvements.

Epilogue

In chapters 5 and 6 I constructed a discourse in which an ethical foundation, basic theories, objectives, practice and characteristics of good care as embodied by professional care providers are described. This discourse was developed on the basis of insights that could be derived from studies on recovery in general (Chapter 2) and my own empirical study (chapters 3 and 4), which had as a special focus the values attributed to professionals by people in the position of client, and which could be derived from the analyses of the narratives.

The logic of good care is embedded in a theory of ethic of care. Building on the work of Tronto and other scholars such as Baart en Van Heijst, I put forward that good care is embedded in a dialectical relationship that is based on human dignity and the wellbeing of people in a vulnerable position. This vulnerable position is always regarded as caused by a combination of personal and social factors. Within the relationship, the notion of care responsiveness is important. Care responsiveness connects the care provider and care recipient. The professional is sensitive towards the narrative of the person, tries to gain full understanding of the person and his or her perspective, and responds and is attuned to his or her expressions. One of these expressions is the needs and desires that came to the fore in the narratives. Good care contributes to the acknowledgement, support and development of identity and autonomy. My study underlines the importance of the theory of recognition as developed by Honneth with the three key elements of love, respect and solidarity.

On the basis of this ethic of care, six fundamental tenets of good care can be distinguished, namely presence, shared perspective, diversity, recognition, autonomy and vulnerability, and empowerment. Each of these areas can be considered separate theoretical frameworks, although they are interrelated. Further research is required to study the precise relationships between the tenets. My assumption is that they are all of equal importance. Ignoring one of them will weaken the foundation of good care. I approach these areas as *tenets*, indicating that in each unique practice the challenge is to use these frames and to discover how they can be applied.

All the elements of good care have combined meanings. They are at the same time social, psychological, symbolical and physical or practical by nature. The way in which the professional behaves and expresses him- or herself can be considered as *acts of expression*. What is appreciated as supportive by the participants in this study is the expression of understanding, faith and hope. It is the expression of hearing the basic appeal, which is often hidden beneath the surface and has to be excavated and heard. It is the expression of the value of the other.

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Samenvatting

Het boek bestaat uit zes hoofdstukken. Na een inleidend hoofdstuk worden in hoofdstuk 2 de resultaten gepresenteerd van een systematische review van herstelstudies in de afgelopen 15 jaar.

In de hoofdstukken 3 en 4 worden de resultaten van een kwalitatief empirisch onderzoek beschreven. Hierin staan 13 verhalen van mensen met langdurige ervaringen met geestelijke gezondheidszorg centraal. De studie was gericht op zowel hun persoonlijke verhaal als op hun opvattingen over wat hen daadwerkelijk hielp in hun herstelproces. Het doel van de studie was om te achterhalen wat er met hen gebeurde in termen van levensgebeurtenissen en het ontstaan en verloop van de psychische aandoening, hoe de persoon omging met zijn kwetsbaarheid en wat de rol van de omgeving was. Ik was vooral nieuwsgierig om te weten welke factoren belemmerend of bevorderend waren voor vooruitgang.

In de analyse was er bijzondere aandacht voor de rol van de geestelijke gezondheidszorg. Welke diensten vonden de deelnemers aan het onderzoek behulpzaam? Wat wordt door hen beschouwd als 'goede zorg'?

Hoofdstuk 3 beschrijft aspecten van kwetsbaarheid en herstel zoals die naar voren kwamen uit de analyse. In hoofdstuk 4 worden de resultaten van een secundaire analyse gepresenteerd. In deze analyse zocht ik naar essentiële noties in de interactie tussen de deelnemers en professionals. Ik onderzocht de thema's in de verhalen die gekoppeld zijn aan goede zorg. In hoofdstuk 5 zijn de inzichten van de narratieve studie uitgewerkt naar een ‘theorie van goede zorg’. Hierbij zijn er verbindingen gemaakt met andere relevante onderzoeken en theorieën. In hoofdstuk 6 is een vertaling gemaakt vanuit de theorie naar een praktijk van goede zorg.

Hoofdstuk 1

Hoofdstuk 1 beschrijft de doelstellingen, de achtergrond en het methodologische ontwerp van dit onderzoek. De studie had als doel om:
1. bij te dragen aan de kennis over herstel en professionele ondersteuning bij herstel;
2. bij te dragen aan theorievorming over goede zorg (voor kwetsbare personen) op basis van een ethiek van zorg.
3. bij te dragen aan de ontwikkeling van ‘praktijken van goede zorg’ door het identificeren van essentiële elementen van goede zorg.

Decennia lang hebben wetenschappers onderzoek verricht naar, gesproken en geschreven *over* mensen met een psychische aandoening. De invloed van ‘consumenten’ in zowel praktijk als onderzoek is de afgelopen decennia aanzienlijk toegenomen. Onder invloed van de rehabilitatie- en herstelbeweging worden hun persoonlijke ervaringen nu meer en meer gehoord. Hun positie verandert van een passief object tot een actief subject. Ze bewegen zich van de rol van een patiënt, cliënt of consument naar de rol van een expert-door-ervaring, een co-researcher of een peer specialist.

Er is een nieuw soort wetenschappelijke kennis aan het ontstaan: experientiële kennis. Deze complementeert andere wetenschappelijke bronnen. In hoofdstuk 2 wordt een

overzicht gegeven van de studies die de afgelopen jaren in een aantal landen gedaan zijn vanuit dit voor de wetenschap nieuwe perspectief. Voor de professionele praktijk betekent dit dat de relevantie en het belang van persoonlijke ervaringen en de conceptualisering van de persoon van zijn huidige en toekomstige situatie centraal komt te staan.

Aansluitend bij deze ontwikkeling besloot ik, aanvullend op wat er al bekend is uit internationaal onderzoek, in Nederland een empirische kwalitatieve studie uit te voeren. Hierbij verzamelde en analyseerde ik verhalen van mensen die ernstige psychische problemen hebben ervaren of nog steeds ervaren. Naast dat ik wilde leren over factoren die herstel belemmeren of bevorderen, wilde ik leren van hun ervaringen met de geestelijke gezondheidszorg. Ik was er van overtuigd dat door op een grondige wijze vanuit 'cliëntperspectief' data te verzamelen en te analyseren, bewijs zou kunnen worden gevonden over factoren die echt bijdragen aan gezondheid en welzijn.

Voor het onderzoeksdesign besloot ik een analyse te maken op basis van enkel de ervaringen van zorggebruikers en geen onderzoek te doen onder professionals, zodat de experientiële data niet 'vervuild' zouden worden. De empirische data zijn gebruikt voor een conceptuele analyse, waarbij de methodologie van grounded theory is toegepast. Grounded theory is een kwalitatieve onderzoeksbenadering waarbij op basis van empirische data nieuwe inzichten in fenomenen en innovatieve theoretische formuleringen worden ontwikkeld. (Glaser & Strauss, 1967).

Hoofdstuk 2

In hoofdstuk 2 beschrijf ik de resultaten van een literatuurreview. Hierbij heb ik twee typen studies naar herstel betrokken. Het eerste type wordt gevormd door de 'traditionele' longitudinale studies, die voor het merendeel gericht waren op objectieve maten zoals symptomatologie en sociaal functioneren. Het tweede type betreft de moderne kwalitatieve experientiële studies, die vooral gericht zijn op subjectieve ervaringen.

Het hoofdstuk begint met een samenvatting van de uitkomsten van 15 longitudinale studies tussen 1969 en 2001. Vervolgens wordt een review gepresenteerd van 28 kwalitatieve studies die gepubliceerd werden tussen 1993 en 2009. Het hoofdstuk eindigt met de resultaten van een clusteranalyse.

Longitudinale studies

Het verloop van ernstige psychische aandoeningen wordt al meer dan een eeuw bestudeerd. Vooral tot aan de tachtiger jaren van de vorige eeuw werden veel longitudinale studies uitgevoerd, vooral naar schizofrenie (bijvoorbeeld Ciompi, 1980; Strauss & Carpenter, 1974; Strauss *et al.*, 1978). In de eerste paragrafen van hoofdstuk 2 wordt een overzicht gegeven van deze studies. Deze studies hebben meestal een klinische invalshoek, waarbij herstel vooral vanuit een medisch perspectief werd benaderd, hoewel ook wel sociale dimensies meegenomen werden.

Hoewel er verschillende definities van herstel worden gebruikt keken deze studies over het algemeen naar de reductie van symptomatologie en verbeterd sociaal functioneren. De conclusie is dat bij een significant deel van de gevolgde personen een aanzienlijke afname

van symptomen te zien was en/of een verbeterd sociaal functioneren. Gemiddeld genomen blijkt dat hoe langer de periode sinds het ontstaan van de ziekte, hoe groter het percentage mensen dat herstelt.

Uit een grote meta-analyse van Harrison *et al.* (2001), waarbij het ging om meer dan 1.600 mensen uit meer dan 10 landen in Azië, Europa en Noord-Amerika blijkt dat bij een significant deel sprake was van gunstige lange termijn uitkomsten. Metingen na 15 en 25 jaar laten zien dat meer dan de helft van de mensen in meer of mindere mate herstelt, hoewel er grote variaties waren in de verschillende uitkomstdimensies. Een ICD-10 diagnose schizofrenie bleek gerelateerd aan slechtere uitkomsten wat betreft symptomen, sociale beperkingen en gebruik van hulpbronnen. Hoewel er verschillen zijn tussen culturen is het mortaliteitsrisico voor mensen met schizofrenie en gerelateerde psychotische aandoeningen hoog in praktisch alle landen waar studies verricht zijn. Voor alle uitkomstmaten was het percentage tijd waarin men psychotische symptomen ervoer in de twee jaar na het ontstaan van de aandoening de beste voorspeller. Hoe korter de tijd met psychotische symptomen, hoe beter de herstelprognose.

Meer recente studies laten zien dat een combinatie van inspanningen zo snel mogelijk nadat een psychose zich voor de eerste keer voordoet, de tijd die nodig is voor symptomatologisch herstel significant vermindert, waardoor er ook een gunstig effect optreedt op sociaal herstel (bijv. McGorry, Killackey & Yung, 2008).

Belangrijke factoren lijken te zijn: voorkoming van ziekenhuisopname of het beperken van opname tot het minimum, het organiseren van adequate steun van het sociale netwerk, en het bieden van goede medicatie, voorlichting, begeleiding en ambulante zorg.

Experientiële studies

Sinds het eind van de tachtiger jaren van de 20ste eeuw werd een toenemend aantal persoonlijke verhalen gepubliceerd. Mensen begonnen te schrijven over hun eigen herstelproces. Vanaf de jaren negentig begonnen wetenschappers en professionals steeds meer geïnteresseerd te raken in de fenomenen van persoonlijk herstel, en begonnen zij hiernaar onderzoek te doen en hierover te publiceren. Gedurende de laatste 20 jaar verscheen een groeiend aantal studies waarin de ervaringskennis van mensen in allerlei landen gebundeld werd.

De meeste studies bevatten een analyse van persoonlijke narratieven en gebruikten een grounded theory benadering om noties te ontwikkelen over fenomenen die geassocieerd kunnen worden met herstel, het verloop van een herstelproces en factoren die dit proces beïnvloeden. Ik selecteerde 28 verschillende studies, die betrekking hebben op meer dan 950 personen in 11 landen. De belangrijkste bevindingen zijn de volgende.

Een ernstige psychiatrische aandoening kan veroorzaakt worden door verschillende biologische, psychologische en sociale factoren. Zij veroorzaakt ernstige verstoringen waar een persoon mee om moet zien te gaan. Het betreft onder andere een verstoorde waarneming, aandachtstoornissen, verlies van ego-grenzen en een gevoel van vervreemding; verstoord denken, en verstoringen in emoties, gedrag en relaties.

De impact van geestelijke gezondheidsproblemen op het sociale leven is groot. Zo worden relaties met partners, kinderen, ouders en vrienden beschadigd. Veel mensen rapporteren

ernstige gevolgen op hun (potentiele) carrière. Bovendien is stigmatisering een groot probleem.

Het actief zoeken en vergroten van de controle over de psychiatrische ervaring zijn belangrijke stappen in het herstelproces. Maar bovendien dienen mensen om te leren gaan met de omgeving, of het nu de omgeving van de hulpverlening is, het sociale netwerk of de samenleving.

Een aantal studies laten patronen zien in een herstelproces. Over het algemeen kan herstel gezien worden als een proces van ontwikkeling en reconstructie. Dit proces loopt van het eerste ontstaan van de aandoening, die vaak vergezeld wordt door een staat van ernstige crisis en desintegratie van het zelf, naar een staat waarin de persoon weet om te gaan met de ziekte en zijn gevolgen, of naar algeheel herstel (gedefinieerd als de afwezigheid van ziekte).

Gedurende dit proces zien we twee parallelprocessen. Het ene is het proces waarin de persoon leert om te gaan met zichzelf en het andere is het proces van het weer aansluiting vinden bij de wereld. Heraansluiting is een woord dat goed de focus van beide processen weergeeft. Mensen dienen weer aansluiting te krijgen bij zichzelf, hun kernidentiteit te vinden, controle te krijgen over hun beperking en hun leven. Zij dienen ook weer aansluiting te krijgen bij de wereld om hen heen zoals hun sociale netwerk, de school, de buurt, en het werk.

Fases en transities

Het feitelijke herstelproces kan getypeerd worden in een drietal *fases*. In de eerste fase (*stabilisatie*) is de belangrijkste taak om controle te krijgen over de ziekte zelf.

In de tweede fase (*heroriëntatie*) is een belangrijke taak om een referentiekader te ontwikkelen om de ervaringen rond en ten gevolge van de ziekte te begrijpen, en om een positief toekomstperspectief te ontwikkelen. Dikwijls wordt in deze fase teruggekeken naar het verleden en vindt verwerking plaats van trauma's en verlies. De persoon werkt aan psychologisch herstel. Deze fase omvat het bepalen van de delen van het zelf die intact zijn gebleven, het inventariseren wat belangrijke persoonlijke waarden zijn, en het inventariseren van mogelijkheden (krachten, kwaliteiten) en beperkingen.
In deze periode kunnen verschillende activiteiten plaatsvinden, zoals het verwerven van kennis over de aandoening, over beschikbare hulpbronnen (zoals ggz-diensten), het verwerven van 'herstelvaardigheden', het in aanraking komen met mensen met wie ervaringen gedeeld kunnen worden en het betrokken raken bij zelfhulpgroepen

De persoon werkt aan het opbouwen van een positieve identiteit. Dit houdt o.a. in het bepalen van en het toewerken naar het realiseren van doelen die voor de persoon van belang zijn. In deze fase worden vaak oude doelen en waarden tegen het licht gehouden. Deze periode omvat ook het nemen van verantwoordelijkheid voor het managen van de ziekte, het zorgen voor de eigen beperkingen en het op die manier weer regie krijgen over het eigen leven. Het houdt ook in dat er risico's genomen worden. Er kan terugval plaatsvinden, waarbij men opnieuw probeert er bovenop te komen.

Al deze ervaringen vormen de voorbereiding voor de derde fase (*re-integratie*). In deze fase zet de persoon stappen om rollen te vervullen die zingevend en productief zijn, en die gewaardeerd worden door de samenleving.

Gedurende het proces worden veranderingen gemarkeerd door *veranderpunten* of *transitieperiodes*. Ik identificeerde verschillende typen transities. De eerste verandering vindt plaats 'op de bodem van de put', wanneer mensen besluiten dat de situatie niet langer leefbaar is en moet veranderen. In veel studies komt naar voren dat het startpunt van een herstelproces vaak een situatie van grote wanhoop is. Een tweede type transitie vindt plaats als mensen gebruik konden maken van een geïntegreerd behandel- en rehabilitatieprogramma, die hen helpt *grip* te krijgen op de situatie en hen *aanmoedigt* om aan herstel te werken.

Een derde vorm van transitie wordt gekenmerkt door een (groter wordende) 'sense of agency', een gevoel dat men weer in staat is tot autonoom handelen. Hierbij zien we dat mensen zich actief gaan inzetten om goed voor zichzelf te zorgen, leren met hun beperkingen om te gaan en andere stappen nemen in hun herstelproces. Dit wordt dikwijls voorafgegaan of vergezeld door inzicht of zelfacceptatie.

Het vierde type transitie vinden we verderop in het proces, wanneer mensen zich hebben aangepast aan de beperking in die mate dat zij zich sterk genoeg voelen om een verandering te initiëren in een van de *sociale domeinen* van wonen, werken, opleiding of relaties.

Clusters van herstelfactoren

Een analyse van factoren die bijdragen aan herstel resulteerde in vijf clusters, die samen een *multidimensionaal model* vormen.

1. Factoren die persoonlijke motivatie geven om herstel te initiëren en voorwaarts te gaan.
2. Factoren die bijdragen aan de reconstructie van de identiteit.
3. Factoren die behoren tot het ontwikkelen van competenties om met de ziekte en de omgeving om te gaan.
4. Factoren die leiden tot sociaal engagement.
5. Omgevingsfactoren die dienen als hulpbronnen voor herstel.

Motivationele factoren die behoren tot het eerste cluster zijn o.a. de wens hebben om controle te krijgen over de ziekte en zijn gevolgen, de wil om zingeving te creëren, om positieve levensveranderingen te bewerkstelligen, hoopvol zijn en geloven dat herstel mogelijk is.

Factoren die behoren tot het tweede cluster, het ontwikkelen van de identiteit, zijn bijvoorbeeld: het scheiden van symptomen en omgevingsfactoren van de persoonlijkheid, het toekennen van betekenis aan levenservaringen, het ontdekken van persoonlijke krachten, en het incorporeren van de ziekte in een nieuwe (positieve) identiteit.

Het ontwikkelen van competenties om zich aan te passen aan de beperking, het derde cluster, omvat: het leren van vaardigheden om met de ziekte en de gevolgen om te gaan ('copingvaardigheden'), het ontwikkelen van competenties om het leven en de identiteit in een (nieuw) perspectief te plaatsen, en het ontwikkelen van zelfzorg en sociale vaardigheden.

Factoren die bijdragen aan het veranderen van de sociale status en het opnieuw verbinding vinden met de samenleving, het vierde cluster, omvatten het ondernemen van zingevende activiteiten, het oppakken van sociale rollen en zich engageren in positieve relaties.

Een vijfde cluster bevat omgevingsbronnen zoals steunende relaties, materiele bronnen (huisvesting, inkomen) en geestelijke gezondheidsbronnen (bijv. medicatie, psychotherapie en begeleiding). Geestelijke gezondheidszorgvoorzieningen dienen *responsief* te zijn, hetgeen betekent dat zij op een adequate en flexibele manier tegemoet moeten komen aan de behoeften van de persoon. Indien opname nodig is dan dient deze plaats te vinden in een veilige, vriendelijke en de minst beperkende omgeving. Hulpverlening moet bijdragen aan het vergroten van de competentie om met de kwetsbaarheid en levensstress om te gaan, en begeleiding te bieden om identiteitsvragen te exploreren. De aanwezigheid en steun van professionals is belangrijk – professionals die echt om de persoon geven en positieve verwachtingen hebben. Wat ook gewaardeerd wordt is een positieve en bemoedigende manier van werken, en het scheppen van voldoende ruimte voor 'het herstelverhaal', zelfregie en zelfontwikkeling. Professionals worden gewaardeerd die de persoon respecteren, zijn ervaringen erkennen, zich richten op krachten en geloven in mogelijkheden.

Op een praktisch niveau worden professionals gewaardeerd die datgeen waar de persoon (echt) behoefte aan heeft herkend, die zich (extra) inspannen voor de persoon, die effectieve adviezen geven, en die diensten van goede kwaliteit verlenen.

Relatie tussen clusters

In de interactie tussen clusters, en in de interactie tussen factoren in verschillende clusters, komen veranderingen voor die kunnen leiden tot voor- of achteruitgang. Veranderingen kunnen in alle clusters optreden. Een factor in het ene cluster kan een factor in een ander cluster versterken. Het lijkt er op dat in de loop van de tijd een positieve transitie optreedt als een aantal factoren uit verschillende clusters sterk genoeg zijn. Herstel kan beschouwd worden als een *spiraalvormig* ontwikkelingsproces.

De (clusters van) factoren beïnvloeden en versterken elkaar. Zo heeft bijvoorbeeld het ontwikkelen van sociale vaardigheden (competenties) een gunstige invloed op zelfvertrouwen (motivatie). Door positieve feedback te krijgen (sociale steun), bijvoorbeeld als een nieuwe sociale rol opgepakt wordt (veranderen van de sociale status), is dit bevorderend voor de empowerment (versterking motivatie en identiteit), hetgeen weer kan leiden tot nieuwe stappen c.q. versterking van andere factoren.

De relatie tussen intrinsieke en extrinsieke factoren, en de relatie tussen motivatie, competenties en sociale participatie vergt meer onderzoek. Het is nog niet duidelijk hoe verschillende elementen samenkomen in de loop van een herstelproces. We nemen aan dat bij iedere persoon er sprake is van een andere compositie. Indien de diverse elementen *synchroniseren*, bijvoorbeeld als iemand de juiste steun ontvangt op een tijdstip dat de persoon ontvankelijk is voor verandering, dan vindt ontwikkeling plaats.

Empowerment

In het herstelproces lijkt de notie van *empowerment* een rode draad te vormen. Deze notie kan verbonden worden met alle clusters. Het proces kan worden gekarakteriseerd door een continue en groeiende empowerment. Door competenties te verwerven wordt empowerment vergroot. Door versterking van de identiteit kunnen transities gemaakt worden naar zinvolle activiteiten en sociale rollen. Materiele en persoonlijke steun vormen externe krachtbronnen die de ontwikkeling van innerlijke kracht bevorderen en zo bijdragen aan zijn of haar herstelproces.

Mensen kunnen macht en controle krijgen over hun levens door toegang te krijgen tot zinvolle keuzes en de bronnen om deze keuzes te implementeren. De bevindingen documenteren de cruciale rol die *keuzemogelijkheden* spelen bij empowerment. Het hebben van informatie over en toegang krijgen tot een variatie aan zinvolle en nuttige opties bevorderen herstel.

Deelnemers worden empowered als zij keuzes maken met betrekking tot waar te wonen, financiën, werk, leefstijl, relaties, zelfmanagement en hulpverlening. In het kader van empowerment moeten zinvolle opties wel voorhanden zijn; mensen hebben naast informatie soms training en ondersteuning nodig om keuzes te kunnen maken. Veel te vaak lijken mogelijkheden om kwaliteit van leven te vergroten buiten bereik te zijn. Opties zijn beperkt, van slechte kwaliteit, of bestaan helemaal niet. Deelnemers aan de studies noemden voorbeelden van hulpverleners, familieleden en maatschappelijke instanties waarbij sprake was van dwang, uitsluiting, discriminatie en stigmatisering.

Herstel is een persoonlijk en sociaal proces dat plaats vindt in een strikt individueel tijdsperspectief. Hoe snel of langzaam dit proces verloopt is onvoorspelbaar. Uit de studies wordt duidelijk dat te veel externe tijdsdruk het proces kan beschadigen. Omgevingssteun dient precies aan te sluiten bij de fase van het proces en de behoeftes die samenhangen met wat belangrijk is voor deze persoon in deze specifieke fase, kijkend naar welke (clusters van) factoren versterkt kunnen worden.

Hoofdstuk 3

In de hoofdstukken 3 en 4 worden de resultaten van een kwalitatieve empirische studie beschreven, gebaseerd op de herstelverhalen van 13 personen. De studie vond plaats onder mensen met langdurige ggz-ervaringen in Nederland, en was gericht op zowel hun persoonlijke verhaal als hun opvattingen over wat hen hielp in hun herstelproces. Het doel van dit deel van het onderzoek was om uit te vinden wat hen overkomen was in termen van levensgebeurtenissen en een psychische aandoening, hoe de persoon[74] omging met kwetsbaarheid, en wat de rol van de omgeving was. Ik was in het bijzonder nieuwsgierig naar de factoren die vooruitgang hinderde of bevorderde.

[74] Ik gebruik in dit boek het woord 'persoon' om de mensen aan te duiden die bereid waren hun verhaal te vertellen ten behoeve van dit onderzoek, en op deze wijze hun ervaringskennis ter beschikking stelden zodat meer inzicht verkregen kon worden in herstelprocessen en elementen van goede zorg. Soms refereer ik aan hen als 'cliënt', als zij zich in de rol van zorgontvanger bevinden.

In de analyse was er special aandacht voor de rol van de geestelijke gezondheidszorg. Welke diensten hebben de deelnemers ervaren als helpend? Wat werd door de deelnemers beschouwd als 'goede zorg'?

De verhalen waren niet alleen indrukwekkend, omdat ze stuk voor stuk getuigen van grote (veer)kracht, maar bevatten ook een schat aan gegevens. De resultaten van de analyse van deze verhalen ondersteunen veel van de bevindingen van de review in hoofdstuk 2, maar leveren ook verdiepende inzichten op.

Voor de meeste van de deelnemers aan deze studie was herstel een ambivalente notie. Zij spraken niet zozeer over 'herstel' maar gebruikten andere bewoordingen. Het proces werd beschreven als een proces van *strijd* en *overleven*, een proces om *balans* te vinden, en een proces van *ontdekking*. Anderen spraken over herstel als een proces van *recreatie* en *re-integratie*, zowel in termen van de reconstructie van de identiteit, als in termen van opnieuw deel uit gaan maken van de sociale wereld.

Het is duidelijk dat herstel geen lineair proces is, maar wordt gekarakteriseerd door instabiliteit, met stappen voorwaarts en achterwaarts, met ups en downs. Gezien in het perspectief van de tijd is herstel over het algemeen een langdurig proces, hoewel er sprake is van een grote variantie. Er waren deelnemers die binnen een of twee jaar naar een fase van re-integratie waren toegegroeid, terwijl anderen aangaven dat hen dit tien jaar of langer had gekost. Soms vonden veranderingen snel plaats, soms namen transities meerdere jaren in beslag.

Klaarblijkelijk zijn er twee deelprocessen die herstel vormen. Het ene is het proces van *persoonlijk herstel* wat ook wel het 'terugwinnen van het zelf' genoemd kan worden. Dit deelproces bestaat uit twee belangrijke opgaves: (1) controle herwinnen en zorg dragen voor de kwetsbaarheid, en (2) identiteit ontwikkelen. Dit leidt tot (meer) zelfcontrole, en tot een sterkere en meer geïntegreerde identiteit.

Het andere deelproces is het proces van *sociaal herstel*. Hier is de opgave om te werken aan sociale integratie: deel uit gaan maken van de samenleving. De uitkomsten van het eerste deelproces zijn bewustwording van persoonlijke kwaliteiten (ervaringen, kennis, vaardigheden, talenten en aspiraties) en competenties om met persoonlijke kwetsbaarheid om te gaan. De resultaten van het tweede deelproces zijn participatie, gewaardeerde sociale rollen en zinvolle activiteiten.

De fases (stabilisatie, re-oriëntatie en re-integratie) en de transities in het herstelproces, zoals beschreven in Hoofdstuk 2, kunnen ook herkend worden in de narratieven in deze studie. Het herstelproces is een constant *interactieproces*. Interactie heeft twee elementen: interactie met het zelf en interactie met de sociale omgeving. Mijn analyse bevestigt de bevindingen van Ochocka *et al*. (2005), die een succesvolle 'bemiddeling' tussen deze twee typen interacties beschouwt als essentieel voor herstel.

De interactie met het zelf kan gezien worden als een zelf-dialoog, waarin de centrale thema's zijn: het vinden van betekenisgeving rond hetgeen gepasseerd is (de crisis, de ziekte, het trauma), en het verwerken er van. In alle verhalen in deze studie komen deze thema's terug. Het proces van het construeren of reconstrueren van het levensverhaal lijkt cruciaal te zijn voor verdere ontwikkeling.

Kwetsbaarheid en persoonlijke niche

Een onderdeel van het herstelverhaal is het begrijpen van de eigen *kwetsbaarheid*. Het begrijpen wat de kwetsbaarheid is en hoe zij in elkaar zit maakt het gemakkelijker om een weg te vinden om met de kwetsbaarheid en haar gevolgen om te gaan. Uit mijn analyse komt de notie van de *persoonlijke taak* naar voren. Dit kan gedefinieerd worden als de dagelijkse worsteling met de eigen kwetsbaarheid, het streven de balans te bewaren en niet 'onderuit' te gaan. Dit is een taak die alleen door de persoon zelf kan worden uitgevoerd, maar steun van buiten is vaak nodig, bijvoorbeeld in de vorm van medicatie of een 'waker', iemand die een oogje in het zeil houdt.

Ik introduceer hier de notie van de *persoonlijke niche*, die ik primair definieer als een psychologische zone in en waardoor een persoon zich redelijk comfortabel voelt en een staat van balans kan handhaven. Dit is een constellatie van zelfreguleringsmechanismen met betrekking tot de management van stress en energie. Een persoonlijke niche is individueel en uniek. Het is een beschermd milieu die veilig is en zekerheid biedt. Deze niche is eigendom van en wordt bestuurd door de persoon zelf. Als men buiten de grenzen treedt dreigt overbelasting. Deel van het herstelproces is de grenzen van de niche te leren kennen en manieren te vinden om binnen deze grenzen te blijven. In de persoonlijke niche is stress afwezig of gereduceerd tot een acceptabel niveau. De niche is niet 'betreedbaar' door anderen, dat wil zeggen dat iemand anders er niet mag binnenkomen. Materiele aspecten van de niche hebben in de meeste gevallen betrekking op het bezitten van een eigen fysieke ruimte, zoals een kamer of huis dat privacy biedt, een ruimte waarover men zelf zeggenschap heeft.

Het vraagt vaak actieve fysieke en psychologische inspanningen om een evenwicht te bewaren. Zo blijkt voor veel mensen belangrijk een vast dagritme te handhaven en voldoende rust in te bouwen. Het ontdekken en bepalen van de persoonlijke niche, het verkrijgen van inzicht in hoe dingen van binnen werken, zijn noodzakelijk om efficiënte beheersstrategieën te ontwikkelen en toe te passen.

Het omgaan met de kwetsbaarheid is een belangrijk aspect van individuele ontwikkeling. Indien men in staat is om op een adequate manier hiermee om te gaan, betekent dit dat de mogelijkheden om deel te nemen aan zinvolle activiteiten en rollen toenemen. Uit de verhalen blijkt dat zodra iemand in staat is om zijn of haar persoonlijke niche te beheren, dit de basis vormt voor een verandering van sociale status.

Sociale steun en sociale niches

Het andere interactie element is de interactie met de sociale omgeving. Sociale bronnen zijn voor veel verschillende doeleinden nodig. Zij dienen als steun in de processen die ik eerder noemde: het proces van omgaan met crisis, overleven, identificeren en beheren van de kwetsbaarheid; het proces om rust en stabiliteit te vinden; het proces van het ontdekken en creëren van het eigen levensverhaal; en het proces van het recreëren van de identiteit, en re-integratie in zinvolle activiteiten en sociale rollen.

In dit opzicht vervullen andere mensen de rol van steunpilaar. In de verhalen worden veel verschillende steunende mensen genoemd, zoals familieleden, ervaringsgenoten en hulpverleners.

In het kader van herstel gebruiken veel mensen omgevingen die veiligheid, sociaal contact, steun en erkenning bieden. Dit kunnen omgevingen zijn op het gebied van wonen, werken of andere vormen van dagbesteding. Ik gebruik het concept van de *sociale niche* om dit type milieu te karakteriseren. Dit zijn sociale omgevingen die aangepast zijn of niet interveniëren met de vereisten van de persoonlijke niche. In een sociale niche worden de persoonlijke beperkingen (of in andere woorden de noodzakelijke condities voor sociale participatie) erkend, zodat ruimte geboden wordt voor zinvol sociaal functioneren. Een optimale situatie lijkt te zijn als aan de ene kant de persoonlijke niche gerespecteerd wordt, en aan de andere gewaardeerde sociale participatie gerealiseerd kan worden op basis van interesses, talenten en vaardigheden.

De meeste niches die de deelnemers aan deze studie gebruikten waren gecreëerd door ggz-instellingen. Maar ook 'peer environments', omgevingen zoals cliënt- en herstelinitiatieven, dienden als sociale niche. Er is hier een verschil tussen de meer kwetsbare mensen, waarvan het beheer van de persoonlijke niche vanwege een grote gevoeligheid voor stressfactoren veeleisend was, en de minder kwetsbare personen, wiens persoonlijke niche veel eenvoudiger te managen was.
Bij de laatstgenoemde categorie waren sociale relaties minder gecompliceerd en was hun sociale netwerk veel groter.

De eerstgenoemde groep gebruikte meer faciliteiten die aangeboden werden door ggz-instellingen terwijl de tweede groep meer gebruik maakte van cliënt gestuurde initiatieven.

De narratieven in deze studie onthullen een aantal waardevolle externe *bronnen*, die verdeeld kunnen worden in persoonlijke en materiele bronnen. De deelnemers gebruikten (of hadden gebruikt) verschillende typen omgevingen die relevant waren voor hun herstel. Dit zijn: natuurlijke omgevingen, omgevingen met situatiegenoten en ggz-omgevingen. Een omgeving is herstelbevorderend als deze *faciliterend* is. Faciliterende omgevingen dienen als bronnen voor basisbehoeften zoals huisvesting en sociale contacten. Zij bieden gelegenheid voor activiteiten en sociale rollen. Zij dienen als plekken voor heroriëntatie, bevestiging en ontwikkeling.

Er werden echter ook veel omgevingen genoemd die stress veroorzaakten en beschadigend waren. Het is duidelijk dat de relatie tussen de persoonlijke niche en sociale omgevingen dikwijls ambigue is. Aan de ene kant hebben mensen om verschillende redenen sociale contacten nodig, terwijl aan de andere kant deze interacties stress kunnen geven en potentieel risicovol zijn.

Zoals eerder genoemd is een fysieke gepersonaliseerde ruimte zoals een appartement of een kamer, als onderdeel van de persoonlijke niche, een belangrijke thuisbasis om veiligheid te ervaren. Persoonlijke bezittingen, maar ook huisdieren (die vaak waardevol gezelschap en steun bieden) kunnen deel uitmaken van deze fysieke arrangementen. Evenals in de andere studies zoals besproken in hoofdstuk 2 blijkt ook uit dit onderzoek het belang van het hebben van goede huisvesting en voldoende financiële middelen. Het Nederlandse systeem van sociale voorzieningen blijkt hierbij waardevol te zijn.

In de verhalen van de deelnemers spraken zij over de sociale en psychologische factoren die voor hen van betekenis waren. In sociaal opzicht noemden zij het belang van het behoren bij een gemeenschap en het gebruik maken van vertrouwde ontmoetingsplekken

(zoals een dagactiviteitencentrum of een werkplek). Soms was er op deze plaatsen sprake van persoonlijke relaties, soms was er louter een verbinding door het feit dat andere mensen participeerden in dezelfde omgeving. Het zich simpelweg verbonden voelen, al is het maar via het lidmaatschap van een bepaalde gemeenschap, geeft een gevoel van erbij horen, hetgeen belangrijk is in het proces van sociale re-integratie.

Sociale steun is een belangrijke factor voor herstel. Dit kan geboden worden door een individu of in de context van een bepaalde omgeving, bijvoorbeeld de werkomgeving of de omgeving van een ggz-voorziening. Naast de sociale niches die geboden worden door de ggz en andere instellingen zoals maatschappelijke opvang blijken de netwerken van familie, vrienden en ervaringsgenoten of herstelgroepen belangrijke steunsystemen te vormen.

Er komen twee vormen van steun naar voren. De ene is *tijdelijke steun met een grote impact.* Dit type steun komt tegemoet aan een urgente behoefte, bijvoorbeeld de behoefte getroost te worden, om gehoord te worden, of om een urgent probleem op te lossen. Het andere type steun is *langdurige steun*. De analyse laat zien dat continuïteit een belangrijke factor is. Continuïteit wordt tot uitdrukking gebracht doordat mensen de relatie niet verbreken en contact blijven houden. In veel gevallen vervullen familieleden deze rol. Maar ook professionals die een langdurige relatie met de persoon onderhouden worden als zeer steunend ervaren.

Louter de aanwezigheid van mensen, in goede en slechte tijden, blijkt al een belangrijke steunfactor. Op een psychologisch niveau verschaffen deze relaties erkenning en daardoor hoop. Zij bieden ook een verbinding met de wereld, en helpen de persoon op deze wijze bij re-integratie.

Een belangrijke bevinding is dat de persoon de relatie moet ervaren als adequaat met betrekking tot wat nodig is, inclusief de behoeftes die samenhangen met de persoonlijke niche. Naast de fysieke aanwezigheid van anderen, wordt ook beschikbaarheid beschouwd als adequate steun. Dit houdt in dat anderen toegankelijk zijn en benaderd kunnen worden als dat nodig is.

Indien we naar factoren kijken die bijdragen aan *empowerment* dan komen zowel extrinsieke als intrinsieke factoren naar voren. Extrinsieke motivationele factoren kunnen intrinsieke motivatie versterken. Uit mijn analyse blijken relevante intrinsieke factoren o.a. te zijn: het overleven van een crisissituatie, een zekere doeloriëntatie, genoeg zelfvertrouwen, genoeg fysieke en psychische energie, en het geloof dat iemand heeft in zijn eigen mogelijkheden. Deze kunnen allemaal beschouwd worden als innerlijke krachten. Positieve ervaringen in het hier en nu, bijvoorbeeld de ervaring dat een taak succesvol volbracht is, dragen bij aan empowerment. Al deze factoren dragen ook bij aan de ontwikkeling van een nieuw zelfgevoel of, met andere woorden, aan de ontwikkeling en bevestiging van persoonlijke identiteit.

Relevante externe factoren die belangrijke bronnen zijn om vooruit te gaan zijn: anderen die steun, hoop, en aanmoediging verschaffen alsmede mogelijkheden om levensomstandigheden te veranderen, hierbij inbegrepen materiele bronnen als huisvesting en financiële middelen.

Een specifieke factor is erkenning. Dit omvat de erkenning dat je (nog steeds) een menselijk wezen bent, een individu met een eigen identiteit. Een ander element is de erkenning van persoonlijke kwaliteiten zoals talenten, vaardigheden en prestaties. Hiermee samen hangt het (groeiende) besef dat het leven de moeite waard is, en dat er een toekomstperspectief is.

Herstelondersteunende ggz

In het domein van de geestelijke gezondheidszorg zijn waardevolle hulpbronnen onder andere: medicatie waar de persoon goed op reageert, veilige omgevingen en professionals die een persoonlijke relatie aangaan, in combinatie met het bieden van steun die door de person als helpend ervaren wordt.

Professionals worden als helpend ervaren als zij er in slagen op een persoonlijk niveau een verbinding te maken. Een belangrijke bevinding is dat een interactie die gekarakteriseerd kan worden als een vertrouwensrelatie op zichzelf een gekoesterde bron is. Deze professionals hebben een manier om zodanig aan te sluiten bij de persoon dat deze zich gezien en begrepen voelt. Zich gezien en begrepen voelen kan betrekking hebben op verschillende zaken zoals: het lijden, een bepaald probleem en de emoties die samenhangen met het probleem of onder de oppervlakte verborgen liggen.

Professionals die een langdurige betrekking aangaan leveren globaal op drie manieren een bijdrage aan herstel. In de eerste plaats spelen zij een assisterende rol bij het beheer van de persoonlijke niche. In de tweede plaats spelen zij een rol bij persoonlijke ontwikkeling, bijvoorbeeld van de identiteit of van vaardigheden. Zij blijven het proces van heroriëntatie ondersteunen door hoop te bieden, te helpen doelen stellen, plannen te maken en ideeën te realiseren. Zij helpen de persoon krachten te vergroten en vaardigheden en talenten te ontwikkelen.

In de derde plaats spelen professionals een belangrijke rol met betrekking tot sociaal herstel, de verbinding met de wereld. Zij helpen in het proces van re-integratie, bijvoorbeeld door de persoon te ondersteunen bij het deelnemen aan nieuwe omgevingen en het vervullen van nieuwe rollen.

Hoofdstuk 4

In hoofdstuk 4 worden de resultaten van een secundaire analyse gepresenteerd. In deze analyse zocht ik naar essentiële noties in de interactie tussen de verhalenvertellers en professionele hulpverleners. Ik zocht naar thema's in de verhalen die geassocieerd konden worden met 'goede zorg'. Goede zorg definieerde ik als 'zorg die door de ontvanger van zorg ervaren wordt als helpend'. In het Engels gebruik ik het woord 'beneficial', hetgeen ook vertaald kan worden als 'weldadig' of 'voordelig'. Het doet de ontvanger goed en hij kan er zijn voordeel mee doen; het helpt hem vooruit.

De thema's die ik vond kunnen geclusterd worden in vijf categorieën: verbinden, begrijpen, bevestigen, beveiligen en versterken. De categorieën heb ik uitgedrukt in actieve werkwoorden om aan te geven dat het gaat om een actief en dynamisch proces.

(1) Bij de eerste categorie is de kern dat een *persoonlijke verbinding* tot stand komt. Hoewel ik het onderscheid als een aparte categorie, die uit een aantal elementen bestaat, kan verbinding zich alleen ontwikkelen door handelingen in de andere categorieën.

Verbinden kan beschouwd worden als een proces dat kan beginnen met een glimp van sympathie voor de professional en zich in de loop van de tijd verdiept.
Sympathie kan opgewekt worden door de empathische aandacht van de professional, door het respect dat hij/zij toont, of door het gebruik van humor. Het verdiepen van de relatie kan gebeuren dankzij wederkerigheid in de relatie, een continue presentie, en door handelingen van commitment en toewijding. Het verbindingsproces kan resulteren in een gevoel van saamhorigheid of kameraadschap.

De relationele en communicatieve noties die naar voren komen uit het onderzoek creëren een zogenaamde *interpersoonlijke ruimte*. Dit is een psychologische metafoor die een aantal kwaliteiten tot uitdrukking brengt die nodig zijn voor een constructieve samenwerking en om herstel op een goede manier te ondersteunen. In deze veilige ruimte is plek om er te mogen zijn, voor expressie en dialoog, en voor ontwikkeling. Een verbinding en samenwerking tussen de persoon en de professional lijkt alleen tot stand te worden gebracht als er een soort van wederzijdsheid of responsiviteit is van beide kanten.

(2) De tweede categorie is dat een persoon zich *begrepen voelt*. Dit kan begrip zijn van de situatie of van hem- of haarzelf als individu. Zich begrepen voelen versterkt de persoonlijke band met de professional. De notie van begrijpen is verbonden met de sensitiviteit van de professional voor wie de ander als persoon is, diens situatie en ervaringen.
De persoon voelt zich begrepen door de wijze waarop de professional zich uitdrukt. De professional draagt ook bij een beter begrip van de persoon van zichzelf. Dit kan bevorderd worden door de persoon ruimte te geven zijn verhaal te vertellen, door verhelderende vragen te stellen en te helpen ervaringen in een breder perspectief te plaatsen.

(3) Een ander belangrijk aspect is dat de persoon ervaart dat hij *erkend wordt*. Dit draagt bij aan de derde categorie. Nogmaals: dit kan een erkenning zijn van de persoonlijke situatie, van het lijden, maar ook van kwetsbaarheid en kracht. Door deze erkenning voelt de persoon zich gezien en gerespecteerd. Ik gebruik de term *'bevestiging'* om tot uitdrukking te brengen dat door erkend te worden, mensen in kwetsbare posities ook houvast ervaren. Erkend worden als een uniek menselijk wezen betekent dat iemands identiteit wordt onthuld en bevestigd. Tegelijkertijd is het een uitdrukking van waardering en een belangrijke bijdrage aan het vergroten van zelfvertrouwen.

De notie van bevestigen heeft een drievoudige betekenis. De eerste is dat de professional tegemoet komt aan de basale behoefte om erkend te worden als een waardevol menselijk wezen, met een eigen autonomie en een unieke identiteit. De tweede is dat zijn of haar persoonlijke ervaringen en kennis erkend worden (als zijnde valide en waardevol).
De derde betekenis is dat de professional tot uitdrukking brengt dat hij of zij zichzelf 'bevestigt' aan de ander, dat er een verbintenis of engagement aangegaan wordt. Hiermee wordt ook de intentie tot steun uitgedrukt. De persoonlijke-professionele verbinding wordt bevestigd, ook van de zijde van de cliënt.

(4) De vierde categorie is *beveiligen*. Hoewel bevestigen ook een vorm van beveiligen is, omvat beveiligen alle andere elementen die de persoon helpen zich veilig (of veiliger) te voelen. Uit mijn analyse wordt duidelijk dat alleen al de presentie van de professional die

vertrouwd wordt door de persoon al de nodige veiligheid biedt. Daarnaast kwamen verscheidene actieve vormen van beveiligen naar voren uit de studie. Dit varieert van een snelle reactie op een wanhopig telefoontje tot het uitwerken van een signaleringsplan. De verbinding tussen professional en cliënt biedt een vorm van zekerheid, die tegemoet komt aan de behoefte aan zekerheid en iemand te hebben om zich aan vast te houden. Binnen de handelingen die bij beveiligen horen worden ook meer specifieke elementen zichtbaar, zoals assistentie om de persoonlijke niche te beheren en het bieden van geruststelling. Door zijn aanwezigheid in het leven van de persoon biedt de professional zo een vorm van 'sociale zekerheid'

(5) De vijfde categorie heb ik *'versterken'* genoemd. Uit dit onderzoek komt overtuigend bewijs naar voren dat goede zorg gericht is op het sterker maken van mensen en het hen op deze wijze helpen in hun herstel- of ontwikkelingsproces. Versterken start met het zien en erkennen van de sterke (gezonde) kanten van de persoon, en het focussen op mogelijkheden. Cliënten waarderen professionals die een optimistische kijk hebben, die bemoediging en inspiratie bieden. Een belangrijke vorm van versterken is het ondersteunen van mensen om te leren van ervaringen in verleden en heden.

Je zou kunnen zeggen dat beveiligen, begrijpen en bevestigen de basis vormen van een steunende relatie. Hoewel dit bijdraagt aan het gevoel van verbinding, om zich erkend en veilig te voelen, is dit mogelijk niet genoeg voor herstel. Vanuit het perspectief van de deelnemers aan het onderzoek, dienen 'daden van versterking' toegevoegd te worden. Op deze wijze helpt de professional met de drie fundamentele opgaves van herstel: het reconstrueren van de identiteit, het vergroten van de vaardigheden om met de kwetsbaarheid om te gaan, en het restaureren van autonomie en sociale participatie. Belangrijke empowerende daden zijn o.a. het helpen ontdekken van de kernidentiteit door te leren van ervaringen, het benadrukken van talenten en prestaties, het bieden van inspiratie en bemoediging, het werken aan een toekomstperspectief, en het verbinden van mensen met omgevingen die ruimte bieden voor groei.

Hoofdstuk 5

In hoofdstukken 5 en 6 worden de inzichten uit de voorgaande hoofdstukken gebruikt om een theorie van geode zorg te ontwikkelen. Dit gebeurt door deze inzichten te verbinden met andere relevante studies en theorieën. Er wordt een discours geconstrueerd waarvan een ethische fundering, basistheorieën, karakteristieken, doelen, en een praktijk van goede zorg deel uitmaken.

In hoofdstuk 5 worden de ethische fundering en zes opgaves uitgewerkt. Ook worden de doelstellingen van goede zorg beschreven. Dit wordt in hoofdstuk 6 vervolgd met een beschrijving van aspecten van de positie die zowel aan zorgontvanger als zorggever toegekend worden. Ten slotte worden de genoemde uitgangspunten, opgaves, uiteindelijke doelen en positiekenmerken vertaald naar de professionele praktijk.

Ethische fundering

De logica van goede zorg is ingebed in een zorgethische theorie. Voortbouwend op het werk van Tronto en andere wetenschappers als Baart en Van Heijst, breng ik naar voren dat een praktijk van goede zorg ingebed is in een dialectische, wederkerige relatie die gebaseerd is op menselijke waardigheid en gericht is op het welzijn van mensen in een kwetsbare positie (Baart 2001; Tronto, 1993; Van Heijst, 2005). In deze relatie is erkenning essentieel (Honneth, 1995). De relatie is gebaseerd op presentie en de erkenning van de ander als een medemens (de ander als gelijke) *en* als een uniek, speciaal individu (de ander als ongelijke). In dit ethisch kader wordt breekbaarheid (h)erkend en geen geweld aangedaan. De praktijk draait om de erkenning en restauratie van menselijke integriteit en waardigheid.

Goede zorg is zowel gericht op de bescherming van kwetsbare mensen als op inclusie en empowerment. De zorgende relatie draait om de ontdekking van wat beschouwd kan worden als 'goed'. In de ontwikkeling van opvattingen over wat goed is wordt ook duidelijk welke waarde versterkt, gesteund en verkregen zou moeten worden.

Opgaven

Op basis van dit zorgethisch fundament heb ik zes fundamentele opgaves onderscheiden, namelijk: presentie, gedeeld perspectief, diversiteit, erkenning, autonomie en kwetsbaarheid, en empowerment. Elk van deze gebieden kan beschouwd worden als een apart theoretisch raamwerk, hoewel ze ook met elkaar verbonden zijn. Verder onderzoek is nodig om de precieze relatie tussen deze opgaves te bepalen. Mijn veronderstelling is dat zij alle van gelijke importantie zijn. Als een van hen genegeerd wordt zal dit de fundering van goede zorg verzwakken. Ik gebruik het begrip 'opgave' om aan te geven dat in iedere praktijk (zoals gedefinieerd door MacIntyre, 1985) en praktijksituatie de uitdaging is om de principes te gebruiken en te ontdekken hoe deze kunnen worden toegepast.

(1) De kern van de opgave van *presentie* is om op een zodanige wijze aanwezig te zijn dat door de ander weldadigheid ervaren wordt. De opgave is om present te raken, te zijn en te blijven op een zodanige wijze dat een toegewijde verbinding met de persoon tot stand komt. De opgave houdt in dat manieren gevonden worden om dichterbij te komen, om aandachtig te zijn op een open doch geconcentreerde wijze, en om een verbinding aan te gaan met de leefwereld van de persoon (Baart, 2001). Dit vereist kalmte, gevoeligheid en loyaliteit. Het vereist van de professional dat de ervaringen en emoties van de ander toegelaten worden, en deze niet te vermijden of weg te duwen. Het vraagt een inspanning om je op meerdere niveaus met de persoon te verbinden, om compassievol te zijn, te zien wat er op het spel staat, en te doen wat gedaan moet worden. Uit mijn studie blijkt dat louter de presentie van de professional al bijdraagt aan bevestiging, veiligheid en versterking.

(2) De opgave van het creëren van een *gedeeld perspectief* hangt samen met de categorieën verbinden en begrijpen. Deze opgave is bedoeld om het mogelijk te maken dat een verbinding tot stand kan komen tussen de twee perspectieven van professional en cliënt. Goede zorg kan alleen maar tot stand komen door middel van een dialoog tussen het perspectief van de persoon en dat van de professional. De opgave van gedeeld perspectief beoogt een inter-relationele ruimte van gezamenlijk begrijpen te creëren. De kern van de notie is dat de professional in staat is om zich te verplaatsen in de positie van de ander zodat deze (beter) begrepen kan worden. Dit dient drie doeleinden. De eerste is om de ander en zijn behoeftes echt te begrijpen. De tweede is om in staat te zijn een relatie te creëren

waarbinnen goede zorg mogelijk wordt. Het derde doel is om jezelf, als professional, te zien vanuit de positie van de ander. Dit stelt je in staat om het eigen gedrag te monitoren door het effect dat het heeft op de ander vanuit diens perspectief te proberen te begrijpen.

Het bereiken van een gedeeld perspectief kan gerealiseerd worden door een proces van ontdekking en leren. Uit het onderzoek blijkt dat dit proces op zichzelf al een belangrijk deel van goede zorg is. Op deze wijze is het creëren van een gedeeld perspectief zowel *deel van* als een *conditie voor* goede zorg.

(3) Het blootstellen aan het perspectief van de ander en het streven dit perspectief te begrijpen impliceert dat men als professional geconfronteerd wordt met een wereld die vaak nogal verschilt van de eigen wereld. Dit maakt deel uit van de opgave van *diversiteit*. De kern hierbij is dat je er van uit gaat dat de cliënt anders is, dat de cliënt in de gelegenheid gesteld wordt anders te zijn, en dat dit verschil intact gelaten wordt.

De rol en positie van de zorgontvanger zijn anders dan die van een professional. Er kunnen verschillen zijn in geslacht, leeftijd, culturele achtergrond, religie, huiskleur enzovoorts. Ik beschouw ook een andere levensloop, gekleurd door ervaringen met een ernstige aandoening, beperkingen en het (geestelijke gezondheids) zorgsysteem als belangrijke aspecten van diversiteit. Ik gebruik inzichten van Kal (2001), Van Heijst (2005), Ghorashi (2006) en Meininger (2007) om dieper in te gaan op kwesties die gerelateerd zijn aan de erkenning van alteriteit.

(4) De opgave van *erkenning* betekent het zien en bevestigen van de ander als een waardevol menselijk wezen, en het erkennen van zijn ervaringen, behoeftes en verlangens. Teneinde in staat te zijn tot erkenning dient een professional de persoon en zijn situatie te begrijpen, en sensitief te zijn voor de behoeftes die samenhangen met erkenning.
Ik gebruik het werk van Honneth (1995) om verschillende elementen van erkenning te behandelen. Honneth onderscheidt drie vormen van erkenning, namelijk *liefde, respect* en *solidariteit*. Honneth biedt een excellent raamwerk door de noties van identiteit, kwetsbaarheid en autonomie met elkaar te verbinden. Bovendien maakt hij een verbinding met sociale exclusie en inclusie. In liefde herkennen we de daden van verbinding en het bieden van basisvertrouwen en basisveiligheid als middelen om bij te dragen aan de identiteit. Goede zorg is gebaseerd op de sympathie voor een ander menselijk wezen en op compassie met de tragedies die hij of zij meegemaakt heeft. Respect voor de ander draagt bij aan het herstellen van autonomie, wat verbonden is met zelf-determinatie en het bewust zijn van rechten. Solidariteit kan verbonden worden met validering en het bevorderen van zelfachting. Het is ook verbonden met de noties van toewijding en commitment, met present blijven en duurzame steun bieden. Ten slotte kan erkenning worden verbonden met empowerment, omdat het een fundering biedt voor herstel, persoonlijke ontwikkeling en participatie.

(5) De opgave van *autonomie en kwetsbaarheid* bouwt voort op de opgave van erkenning. Goede zorg draagt bij aan het bewaren en restaureren van de autonomie. Autonomie kan opgevat worden als het (her)krijgen van zelfbestuur. Het is gerelateerd aan de noties van control, *agency* en verantwoordelijkheid, waarin mensen gezien worden als bestuurders van hun eigen leven en als verantwoordelijke actoren in de sociale gemeenschap.

Uit de narratieve studie blijkt dat autonomie en afhankelijkheid beide tegelijkertijd naast elkaar kunnen bestaan. Vanwege hun beperking kunnen mensen een deel van hun autonomie toevertrouwen aan anderen. Waar het uiteindelijk om gaat is dat uiteindelijk mensen zelf degenen zijn die controle hebben over beslissingen. Goede zorg laat mensen de regie houden en herstelt zoveel als mogelijk de mogelijkheden controle uit te oefenen. Deze opvatting van autonomie is gebaseerd op het respect voor menselijke waardigheid, vrijheid van zelfbeschikking *en* op de notie van interdependentie. Het vraagt om zowel rekening te houden met krachten als kwetsbaarheden. Vooral het laatste is van belang wanneer ernstige beperkingen menselijke waardigheid en zelfbeschikking in de weg staan.

In mijn studie, evenals in die van anderen, wordt autonomie vooral gevonden in de bevestiging van een sterk zelf, een zelf die geworsteld heeft (of nog steeds worstelt) met de aandoening, maar laat zien dat het mogelijk is een 'normaal leven' te leiden *met* de ziekte en de beperkingen. In staat zijn om over bepaalde consequenties van de kwetsbaarheid heen te komen versterkt autonomie. In dit opzicht is autonomie een emancipatorische notie.

Autonomie is ook verbonden met sociale inclusie. Zij kan alleen gerealiseerd worden als mensen elkaar toestaan te participeren als gewaardeerde, gerespecteerde en aan de samenleving bijdragende leden. Sociale inclusie vraagt om validering en erkenning van diversiteit, evenals om de erkenning van de gemeenschappelijkheid van levenservaringen en gedeelde aspiraties tussen mensen.

(6) Het vergroten van de capaciteiten om zorg te dragen voor de kwetsbaarheid, de ontwikkeling van een autonome identiteit en het vergroten van sociale participatie als vormen van toenemende autonomie kunnen ook beschouwd worden vanuit de opgave van *empowerment*. Voor de professional houdt deze opgave in dat hij de persoon helpt om sterker te worden, zowel individueel als samen met anderen. De opgave veronderstelt een goed begrip van concepten en mechanismen van macht en machteloosheid, zowel in de relatie tussen zorgvrager en zorgontvanger, als in de leefwereld van de persoon, in het gezondheidszorgsysteem en in de samenleving. Ik gebruik noties van Jacobs (2001), Van Regenmortel (2002) en anderen om deze opgave toe te lichten.

In de relatie tussen professional en cliënt is goede zorg gericht op het egaliseren van de machtsbalans. De relatie die zich ontwikkeld in de interpersoonlijke ruimte dient de cliënt te voorzien van mogelijkheden sterker te worden en zich krachtiger te kunnen manifesteren. Krachten dienen (h)erkend te worden en zichtbaar, corrigeerbaar en ontwikkelbaar te worden. Het Engelse woord 'power' betekent zowel kracht als macht. Persoonlijke kracht maakt mensen 'eigenmachtiger', dus in staat autonomer te kunnen functioneren. Maar macht is ook iets dat door anderen toegestaan, gegeven of overgedragen kan worden. In de opgave van empowerment zoals ik die hier definieer is dit zeker het geval. Ik gebruik hier de notie van wederkerige kracht of macht die zich kan ontwikkelen binnen de relatie tussen professional en cliënt (Freedberg, 2009). Macht is geen gegeven feit, maar iets dat zich kan ontwikkelen in de samenwerking tussen verschillende partijen (Israel, Checkoway, Schultz & Zimmerman, 1994).

De rol en bijdrage van professionele zorg kunnen verschillen maar in algemene zin zijn wel de volgende kenmerken te noemen. De eerste is dat de professional niet alleen kijkt

naar tekortkomingen en problemen, maar ook naar positieve aspecten, zoals kennis en vaardigheden waar de persoon over beschikt. Het sterker maken van de persoon kan betrekking hebben op het verbeteren van de gezondheid, het beter omgaan met de ziekte en het vergroten van zelfvertrouwen en sociale vaardigheden.

Het tweede kenmerk is dat de professional bemoedigende communicatie gebruikt. Hij articuleert de waarden die hij waarneemt en stimuleert het gebruik van persoonlijke krachten. Het derde kenmerk is dat de acties van de professional altijd versterkende elementen bevat. De acties van de professional zijn gericht op het versterken van de cliënt, of direct of indirect, door faciliterende bronnen te creëren. Een ander aspect van een empowerende benadering is om de persoon te helpen aan te sluiten bij 'empowerende omgevingen' in de samenleving.
De opgave van empowerment vereist dat goede zorg niet alleen gericht is op een individu, maar ook op groepen, organisaties en de maatschappij. Empowerende zorg houdt ook het creëren en in stand houden van sociale niches in, en het verkrijgen van betere toegang tot en controle over hulpbronnen. In dit opzicht kunnen professionals functioneren als kwartiermakers, bemiddelaars of bruggenbouwers.

Doeleinden

De uiteindelijke doelen van goede zorg zijn fysiek, psychologisch, sociaal en existentieel van aard. Fysieke en psychologische doeleinden hebben betrekking op het bieden van veiligheid, bemoediging, hoop en versterken van krachten en mogelijkheden. De professional biedt dit (al) in de relatie zelf, en gebruikt de relatie en de acties die een antwoord zijn op de behoeftes en aspiraties als een middel of brug om de persoon te verbinden met zichzelf en de wereld (sociale participatie).

In de relatie wordt dit gedaan door gezelschap en verbinding te bieden. Door de sociale aard van goede zorg kan zij een bijdrage leveren aan herstel omdat, zoals blijkt uit hoofdstukken 2 en 3, dit proces voor een groot deel gemedieerd wordt door sociale processen. In dit sociale proces is erkenning van groot belang. Goede zorg helpt de ander om zijn persoonlijke identiteit en waarden te onthullen en te bevestigen.

Goede zorg vormt een brug tussen de persoon en de wereld, ofwel in een smalle betekenis, zoals de verbinding met familie, vrienden, buren of een werkplek, of in een bredere betekenis, zoals de verbinding met de maatschappij en erkend worden als een medeburger. In dit opzicht fungeert de professional niet alleen als een medemens, maar ook als een medeburger. Op een symbolische wijze vertegenwoordigt hij de wereld en kan hij fungeren als een brug tussen de wereld van de persoon en de wereld in het groot.

Het uiteindelijke doel van goede zorg, gezien vanuit het perspectief van de gemeenschap en de maatschappij, is sociale inclusie. Ik beargumenteer dat sociale inclusie een cultuur vergt waarin de elementen van goede zorg gereflecteerd worden. Sociale inclusie vereist respect voor verschillen en de bereidheid van iedere burger om barrières te slechten en ruimte te creëren voor ieders kwetsbaarheid. Sociale inclusie vereist een cultuur waarin ieders kwaliteiten en bijdragen aan sociaal kapitaal gewaardeerd worden.

Hoofdstuk 6

Hoofdstuk 6 schetst aspecten van de positie van zowel zorggever als zorgontvanger, en beschrijft elementen van een praktijk van goede zorg.

Karakteristieken

In een praktijk van goede zorg kunnen de basiskwaliteiten van een zorggever teruggevoerd worden op een ethische basis die de integriteit biedt om er te zijn voor de ander (met behoud van de eigen positie), om diversiteit te respecteren (de ander zien als anders maar niet gek; met erkenning van lijden en kwetsbaarheid; met erkenning van kennis en competenties) en de ander te steunen bij het verbeteren van kwaliteit van leven (tot uitdrukking gebracht in het herstellen en versterken van de identiteit, het zorgdragen voor de kwetsbaarheid en het vergroten van autonomie).

Omdat al deze elementen deel uitmaken van goede zorg vraagt dit een grote mate van bewustzijn. Het vraagt een professionele attitude om een persoonlijk-professionele relatie te *willen* aangaan, om jezelf met toewijding in te zetten, inclusief jouw kennis en toegang tot hulpbronnen die de cliënt zouden kunnen helpen.

Een zorggever dient te beschikken over de communicatieve en relationele competenties om een dergelijke relatie te ontwikkelen. In dit proces zijn begrip en erkenning kernnoties. Door begrijpen en erkennen kan de ander bevestigd worden op het niveau van de identiteit, de behoeftes en verlangens. De twee voornaamste praktische vormen van handelen in een praktijk van goede zorg zijn beveiligen en versterken.

Al deze elementen hebben meervoudige betekenissen. Zij zijn tegelijkertijd sociaal, psychologisch, symbolisch en fysiek van aard. De wijze waarop de professional zich gedraagt en uitdrukt kunnen beschouwd worden als *uitdrukkingshandelingen.*
Wat geappreciеerd wordt als steunend door de deelnemers aan het onderzoek zoals beschreven in hoofdstuk 3, zijn expressies van begrip, geloof en hoop. Deze expressies drukken uit dat het basale appel van de ander begrepen wordt. Dit appel is dikwijls verborgen onder de oppervlakte en moet uitgegraven en gehoord worden. Het is de uitdrukking van de waarde van de ander.

De basisconfiguratie voor goede zorg kan gekarakteriseerd worden als een *partnerschap*. Zorgontvangers vatten goede professionals op als mensen waarmee zij een alliantie of bondgenootschap kunnen vormen. Belangrijke noties hierbij zijn symmetrie, wederkerigheid en interdependentie.

Professionals kunnen verschillende posities innemen. Een gewaardeerde positie is die van kameraadschap of vriendschap. Deze metaforische positie brengt de waarde tot uitdrukking die cliënten hechten aan een professional die dichtbij is, die zich persoonlijk engageert en die bereid is een wederkerige relatie aan te gaan. De positie brengt de intentie tot uitdrukking dat je de ander een goed leven toewenst.

Een ander aspect van de professionele identiteit is burgerschap. Deze positie kan de basis vormen voor vriendschap en maakt het mogelijk meer gelijk te worden en de persoon te verbinden met de samenleving.

Omdat goede zorg een normatieve basis heeft is het belangrijk dat de professional in staat is te reflecteren op wat hij/zij ervaart in de praktijk. Ik gebruik hier het concept van de normatief-reflectieve professional zoals ontwikkeld door Kunneman (1996) en anderen. Een centrale vraag in het discours van goede zorg is: "Is hetgeen ik doe als persoon en als professional weldadig voor de persoon die ik diensten verleen?" Anders gezegd: 'Zijn mijn aanwezigheid en handelingen nu echt helpend voor de ander?' Om deze vraag te beantwoorden is reflectie nodig op de notie 'weldadigheid' en op criteria van 'kwaliteit van leven'. Deze beschouwing wordt beïnvloed door de normen en waarden van professional en cliënt, maar ook door de gemeenschap waarin professional en cliënt zich bewegen, alsmede de maatschappij in zijn geheel.

Drie type professionele kwaliteiten kunnen worden onderscheiden. Het eerste zijn *waarden* waarbij uit de analyse commitment en toewijding, welwillendheid en aandachtigheid naar voren komen. De tweede zijn *dispositie*s zoals openheid (open van geest en op, en van hart), authenticiteit en positiviteit. Een andere dispositie is om benaderbaar te zijn en gestoord te kunnen worden. Het derde type kwaliteiten zijn *competenties*. Naast de competenties die behoren bij het beroepsdomein zijn dit empathische sensitiviteit en responsiviteit.

Praktijk

Het ethische fundament, de opgaven en doeleinden van goede zorg moeten vertaald worden naar de dagelijkse praktijk. Naast de karakteristieken van de zorggever en de positie die hij inneemt, bestaat het discours uit methoden of benaderingen die van het bovenstaande een goede instrumentele vertaling vormen.

Uit mijn analyse komen twee concepten naar voren. De eerste is de notie van de interpersoonlijke ruimte. Deze notie is gekoppeld aan de notie van gedeeld perspectief. Een gedeeld perspectief kan alleen maar ontstaan wanneer er sprake is van wederkerige communicatie. Echt begrip ontwikkelt zich indien er een wederzijds gevoel van verbinding en begrip is, zowel op cognitief als op affectief niveau. Het tweede concept is dat van zorgresponsiviteit, hetgeen nodig is om deze verbinding op meerdere niveaus tot stand te brengen.

De *interpersoonlijke relationele ruimte* is de psychologische en sociale ruimte die de verbinding vormt tussen de persoon en de professional. In deze ruimte is het essentieel dat de professional de persoonlijke niche van de cliënt kent en respecteert. De interpersoonlijke ruimte wordt gekenmerkt door wederkerigheid en onderlinge afhankelijkheid (interdependentie). Beide partijen zijn van elkaar afhankelijk, hetgeen geen negatief maar een positieve factor is. Dit nodigt uit tot een reis om elkaar op een constructieve manier te vinden, in een proces van constructieve communicatie en dialoog.

De kwaliteit van de interpersoonlijke relationele ruimte, die de basis vormt voor diverse vormen van zorg en ondersteuning, wordt bepaald door het proces van *zorgresponsiviteit*. In de notie van zorgresponsiviteit plaats ik de zorgontvanger in de positie van *actor*. Van de zijde van de zorggever betreft het de respons van de cliënt op hetgeen de professional tot uitdrukking brengt met betrekking tot de waargenomen behoeftes. Uit de analyse van de herstelverhalen blijkt dat cliënten reageren op het begrip dat men ervaart en de

gevoeligheid van de professional voor het appel dat gedaan wordt, de wensen en behoeftes. Een ander aspect waar men op reageert zijn de acties die de zorggever onderneemt om tegemoet te komen aan deze behoeftes.

Wat essentieel is in dit proces van de zijde van de professional is dat deze constant monitort hoe de persoon reageert op zijn uitdrukkingshandelingen. De crux van een productieve samenwerking is dat de ander de aanwezigheid van de professional waarneemt als zijnde steunend en (potentieel) helpend en weldadig.

Het concept van zorgresponsiviteit vereist een groot perceptievermogen en een grote mate van gevoeligheid. Responsiviteit wordt niet alleen geuit via verbale communicatie maar ook via non-verbale communicatie. De professional stemt zichzelf constant af op de ander en zijn omgeving. Om een responsieve professional te worden zijn de werkprincipes uit de theorie van presentie waardevol (Baart, 2001, p. 754-757). Deze zijn: zich (laten) vrijmaken, zich (laten) openen, zich (laten) betrekken, zich (laten) voegen, zich (laten) verplaatsen, zich (laten) lenen, zich (laten) beheersen en zich toewijden.

Acht fasen/dimensies

In methodische zin kan de praktijk van goede zorg zich laten uitdrukken in acht fases. Omdat deze fases meer complementair en cyclisch van aard zijn, kunnen ze ook beschouwd worden als dimensies van de praktijk. De fases zijn: (1) voorbereiden, (2) benaderen, (3) in aanraking komen, (4) waarnemen en begrijpen, (5) bevestigen en accepteren, (6) creëren van een gedeeld perspectief, (7) handelen, en (8) evalueren en leren.

(1) De eerste fase is *voorbereiden*. De professional adapteert en internaliseert de principes en waarden van goede zorg. Ik noem dit de voorbereiding voor volledige zorgzaamheid. Ik bedoel hiermee dat de professional een zorgrelatie ingaat op basis van een volledig begrip van de morele en ethische principes, de opgaves die hem te wachten staan, een visie gebaseerd op de doeleinden van goede zorg, en passende posities in te nemen.

Deze notie heeft de volgende connotaties.

1. De professional bereidt zichzelf voor om zich ten volle in te zetten, met de intentie om te doen wat nodig is, op de best mogelijke manier, daarbij gebruik makend van alle beschikbare hulpbronnen.
2. De professional wil de cliënt en zijn situatie nemen zoals hij/zij is, met ‘alles er op en er aan’ (holistische benadering). Hij wil de cliënt primair benaderen als medemens en medeburger.
3. De professional neemt voorzichtigheid en precisie in acht. Hij wil op een aandachtige wijze aansluiting zoeken.

(2) In de tweede fase, *benaderen*, wordt de professional present in de leefwereld van de ander. Benaderen drukt een beweging uit naar de ander toe. De professional wil dicht bij de persoon komen en aanwezig zijn in zijn leefwereld. Hij kijkt naar manieren om contact te krijgen. Dit is niet alleen een fysieke actie maar ook, en vooral, een intentionele en communicatieve inspanning, waarbij rekening gehouden wordt met de kwetsbare situatie en de persoonlijke niche van de cliënt.

(3) In de derde fase, *in aanraking komen*, wordt een eerste aansluiting gerealiseerd. In aanraking komen houdt in dat de stap gezet wordt van present raken in de leefwereld van de ander naar present *zijn*. Er komt een persoonlijke verbinding tot stand met de persoon en zijn omgeving. In deze fase wordt een interpersoonlijke relationele ruimte gecreëerd.

(4) Deze verbinding stelt de professional in de vierde fase in staat om informatie te verzamelen over de persoon en zijn situatie, hierbij gebruik makend van alle zintuigen. In deze fase gaat het om *waarnemen en begrijpen*. Het gaan om inzicht te krijgen in het appel dat de cliënt doet, de betekenis hiervan, kwetsbaarheid, behoeftes en krachten. De professional probeert de cliënt, zijn situatie en wensen goed te begrijpen en dit begrip tot uitdrukking te brengen.

(5) In de vijfde fase, *bevestigen en accepteren*, erkent de professional het appel van de ander, en accepteert hij de verantwoordelijkheid om tegemoet te komen aan dit appel, hetgeen tot uitdrukking gebracht wordt in betrokkenheid en commitment. Hoewel bevestigen en accepteren kunnen worden gezien als aparte handelingen, noem ik ze in samenhang om de transitie helder te maken van de fasen van het vestigen van een relatie en het begrijpen van de ander, die deel uitmaken van het creëren van de interrelationele ruimte, naar de feitelijke acties van de professional.

(6) In de zesde fase wordt een *gedeeld perspectief* gecreëerd. Dit is het proces van het samen creëren van consensus over wat er op het spel staat *en* welke acties gewenst zijn. Vanuit het heden wordt het venster naar de toekomst opengezet; er wordt een punt aan de horizon gekozen om op te koersen.

In deze fase is het essentieel dat het perspectief van de ander voldoende begrepen is. Het is belangrijk dat over de beide aspecten een dialoog gevoerd wordt.

Een gedeeld perspectief wil niet zeggen dat de perspectieven van cliënt en professional geheel samenvallen. Het gaat alleen om dat deel waar inzichten moeten samenvallen om goede zorg mogelijk te maken. Het creëren van een gedeeld perspectief houdt ook in dat in de loop van het proces perspectieven kunnen veranderen, omdat de interactie tussen mensen altijd het eigen perspectief beïnvloedt.

(7) Het creëren van een gedeeld perspectief is een voorwaarde en een regulerende basis voor de zevende fase, waar het gaat om competent *handelen*. De professional helpt op een adequate manier de persoon, waarbij hij gebruikt maakt van zowel zijn eigen kennis, talenten, vaardigheden en hulpbronnen, als die van de cliënt. De steun bestaat uit acties die behoren tot 'beveiligen' en 'versterken'. Beveiligen is een respons op (fysieke, psychologische en sociale) kwetsbaarheid, wat betekent dat zorg gedragen moet worden voor voldoende veiligheid en het beheer van een persoonlijke niche die de persoon helpt om zelfcontrole uit te oefenen, en dient als een basis voor een sociaal leven. Versterken is een respons op het verlangen sterker te worden, zoals in staat zijn beter met de beperking om te gaan, om talenten en vaardigheden te ontwikkelen teneinde zinvolle rollen en activiteiten te vervullen.

(8) Ten slotte is de achtste fase *evalueren en leren*. Omdat zorg een dynamisch proces is dat constant *fine-tuning* vraagt zijn reflectie en leren onmisbaar. Hoewel goede zorg op het moment zelf spontaan goed kan doen, is het ook nodig voortdurend te checken of

inspanningen leiden tot de beoogde doeleinden, en of acties verbeterd moeten worden. Dit betekent dat er constant sprake moet zijn van zorgresponsiviteit.

Het *leren door ervaring* is zowel belangrijk voor de professional als voor de cliënt in zijn of haar ontwikkelingsproces. De professional (en de cliënt) leren van hun ervaringen door hierbij stil te staan, hierop te reflecteren en te kijken naar verbeteringen van het handelen.

Curriculum Vitae

Jean Pierre Wilken was born on 26th February 1958 in Eindhoven, Netherlands. He graduated in andragology (1982), and social and clinical psychology (1985) at Utrecht University. He has been working in the field of mental health care from 1976 - 1996. From 1989 -1996 he worked, besides his work as practitioner, as a researcher and advisor at the National Hospital Institute. He specialised in the field of long-term care and psychosocial rehabilitation. From 1996 – 2007 he was director of Storm Rehabilitation, a European centre for development and education in psychosocial rehabilitation. Since 2002 he is professor of social work at the Faculty of Society and Law at Utrecht University of Applied Sciences.
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